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ABSTRACT

A survey of 33 administrators, 62 teachers, and 44 parents of deaf-blind children, and interviews with 50 deaf-blind adults were analyzed to determine the services needed by this population and to examine demographic characteristics. Demographic factors (age, sex, institutionalization, and geographic distribution) are reviewed, and varying definitions of deaf-blindness are cited. Descriptions of the type and range of services offered are provided and gaps in service delivery are identified, including lack of staff skill in the more sophisticated communication methods (such as fingerspelling or signing). Concerns were voiced by federal officials and state and local administrators over funding, especially when programs are called upon to service increasing numbers of deaf-blind persons with additional severe disabilities. Teachers expressed dissatisfaction with their preparation and predicted low level accomplishments for the students. Parents, for their part, were pessimistic about their children's future development. Deaf-blind adults indicated vocational preparation, communication training, and financial aid as the top three desired services, with social life and recreation most frequently cited as a problem. Data and relevant literature are summarized according to 14 topics, including the education process, the habilitation/rehabilitation process, and alternative living arrangements. A final chapter offers recommendations, including the need for a continued federal presence in the education of deaf-blind youth and for parent education and respite care. (CL)

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NEEDS ASSESSMENT OF SERVICES TO DEAF-BLIND INDIVIDUALS

Department of Education
Contract No. 300-81-0426

FINAL REPORT

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Needs Assessment of Services to Deaf-Blind Individuals

Final Report

Table of Contents

Executive Summary i

I. Introduction 1

II. Purpose and Objectives of the Study 3

III. Description of the Deaf-Blind Population 6

IV. Description of Programs Serving the Deaf-Blind Population 11

V. Methodology 30

VI. Data Analysis 37

VII. Syncretization 63

VIII. Suggested Policies and Options for Implementation 75

References 84

Needs Assessment of Services to Deaf-Blind Individuals

Executive Summary

A one-year study of the deaf-blind people of the United States and of the services available to them have uncovered substantial gains made in their education and large areas of unmet or inadequately met needs.

How large is the deaf-blind population? The answer to that question depends upon the definition used. Using data gathered by the National Center for Health Statistic's annual Health Interview Survey of 1977, the study offers four estimates of deaf-blindness in the civilian, noninstitutionalized population, based upon varying definitions: overall, 734,275; narrowly defined, 41,859; deaf and severely visually impaired, 67,340; blind and severely hearing impaired, 399,677. The parallel rates for the institutionalized population are: overall, 13,182; narrowly defined, 3,451; deaf and severely visually impaired, 3,893; blind and severely hearing impaired, 4,999. Prevalence rates for deaf-blindness (a) are higher for females than for males, (b) are higher for older than younger age groups, (c) and vary widely from region to region in the United States.

Interviews with 20 federal officials, 4 representatives of the Helen Keller National Center for Deaf/Blind Youth and Adults, 2 directors of Regional Centers and Services to Deaf-Blind Children, 8 representatives of programs receiving VI-C funding, 6 representatives of programs not receiving VI-C funding, and 3 directors each of State special education and rehabilitation programs have found a wide variety of services available for deaf-blind children and adults. However, the agencies are concerned about their funding in the next few years. Present facilities are regarded as adequate, but the majority of agencies do not believe they could properly serve larger numbers of deaf-blind persons nor deaf-blind persons with additional severe disabilities in their present facilities and with their presently available resources. Another problem of great concern to those interviewed is communication; few feel that present communication resources are adequate to the needs of deaf-blind persons.

Replies from 33 administrators of educational programs for deaf-blind students indicate that present students frequently have defects in addition to their sensory disabilities, especially mental retardation and brain damage. Administrators believe that they presently do not serve about 10 percent of deaf-blind children in their respective areas. While they regard present funding as generally adequate, most administrators are pessimistic about their future support. Only a minority are dissatisfied with diagnosis, evaluation, curriculum, instructional materials, physical plant, faculty, and staff. However, almost one third of the teachers of younger deaf-blind children do not have bachelor's degrees and staff turnover is a frequently mentioned problem. Administrators are pleased with their interagency contacts, but they find parents of their older students lacking in interest and participation. Administrators would like more placement options than they presently have for their students. As a group, the administrators

worry about the futures of their deaf-blind students; they believe that the students will have difficulties earning a living after completing their educations. Nonetheless, they regard their educational contributions as being of substantial benefit to the students, giving them a greater measure of independence.

The questionnaires returned by the 62 teachers generally support the administrator's observations. They have a poor opinion of their own and their colleagues' preparation for the professional services they are called upon to render. Their students are frequently disabled in addition to their sensory impairments and make slow, if any, academic progress. They would like greater parental involvement, but the teachers are not overly critical of the materials and support services with which they must work. They believe that the major success of the education of deaf-blind students has been the great increase in services. Nonetheless, the teachers predict that few of their students will be able to earn, or even to contribute to, their own living, and that many will not be able to live independently.

The 44 parents who replied to the survey are somewhat above average in education. They are disappointed in their deaf-blind children's educational progress and very pessimistic by the children's future development. They regard communication training as the most critical problem that should be addressed, with social-recreational outlets the secondmost cited problem. They regard the recruiting of good staff as the major educational accomplishment in recent times.

Direct interviews with 50 deaf-blind adults finds them (a) somewhat displeased with their educations, (b) unemployed at a rate near 16 percent, (c) earning far less than the average for adults in general, and (d) fairly pleased with their present living arrangements. They regard earning a living as their greatest problem, with communication a close second. They feel they are most in need of vocational training, financial aid, and communication training. They believe that, for all deaf-blind adults, the two biggest problems center about the lack of social-recreational facilities and difficulties in communication.

Taking into account the data from the surveys conducted and from reviews of pertinent literature, the project staff make the following suggestions for policies to improve services for deaf-blind persons:

A. The federal government should assume the responsibility for annually determining the size and characteristics of the deaf-blind population.

B. A continued federal presence is desirable in the education of deaf-blind children and youth.

C. Encourage States to coordinate deaf-blind services at a decision-making level within their hierarchy of social services.

D. Programs for deaf-blind children's parents should be established to provide them with education and respite care, two areas now seriously lacking.

E. Every State needs to establish and maintain vision and hearing conservation programs, especially for persons who already have sensory impairments.

F. A federal program of job development and job placement is urgently needed to supplement the efforts of State Vocational Rehabilitation agencies and Commissions for the Blind.

G. Increased attention should be given to developing independent-living and alternate-living programs for deaf-blind adults.

H. Research efforts must be funded to identify, invent, and evaluate new methods for overcoming the disadvantages of deaf-blindness.

I. Federal support to recreational programs and services for deaf-blind persons should be increased.

J. The nature of the deaf-blind population demands that a concerted effort be made to provide elder care.

K. The assistance of deaf-blind consumers should be sought in planning all programs specifically directed at serving them.

L. Extend educational support for deaf-blind students from the present upper-age limit of 21 years up to 25 years of age.

NEEDS ASSESSMENT OF SERVICES TO DEAF-BLIND INDIVIDUALS

FINAL REPORT

Chapter I

Introduction

This report is based upon a one-year study of the demographic characteristics of and available services for the deaf-blind population of the United States. The study highlights the advances made in some services and the significant problems that remain in others. It is the first time that such an objective national study of this population has been undertaken. It is jointly sponsored by the Rehabilitation Services Administration (RSA) and Special Education Programs (SEP) of the Department of Education. These two agencies have agreed on the value of developing lifelong plans for this disability group, whose problems transcend the resources of any one agency to solve and whose needs begin with the onset of their condition and persist throughout their lives.

To assist the reader in comprehending the vastness of the problem and to digest the findings from multiple sources, this report has been divided into the seven chapters that follow. The next chapter discusses the purposes and objectives of the study; these have been set forth in the original request for bidders on the contract under which this study has been conducted. Chapter III describes the deaf-blind population demographically, with data derived from surveys conducted by other organizations but consolidated and reconciled in this report. Chapter IV presents observations of the services presently available for serving the deaf-blind population, observations made by others and by the team that conducted the present study. Chapter V describes the methods by which the surveys of administrators, parents, and teachers of deaf-blind students have been conducted, along with a survey of deaf-blind adults. The data analysis is presented in Chapter VI. Chapter VII brings together the data in summary form, and Chapter VIII suggests policies and some ways in which those policies might be implemented.

An executive summary opens the report, in a manner that has become customary in the presentation of such discursive material as has been covered for this study. It is the authors' hope, however, that most readers will delve into the underlying bases for the conclusions and recommendations, since the interpretation of any particular finding is not an automatic consequence of statistical logic or of any one educational or rehabilitation philosophy. Different readers, if they examine the detailed evidence, may well reach other conclusions than those that will be found in the ensuing chapters. That, however, will be in keeping with the authors' intentions. This report is intended to provoke discussions of the available options and thus lead to actions that will alleviate the problems confronting those who are deaf-blind. Drawing attention to the needs of the deaf-blind population is the first step in fulfilling them.

For those interested in pursuing aspects of the problems dealt with in this report, an annotated bibliography has been delivered to the Project Officer for possible dissemination. The references listed at the end of this report are only a small portion of the sizable numbers of publications that have been reviewed in the course of its preparation. Also, estimated cost information is contained in an addendum to this report which will be supplied on request from PSA.

Chapter II

Purpose and Objectives of the Study

In September 1981, the Department of Education's Rehabilitation Services Administration (RSA) and Special Education Programs (SEP) contracted with Rehabilitation and Education Experts, Inc. (REDEX) to conduct a needs assessment of services to deaf-blind persons. This study, conducted over a fifteen-month period, has been an attempt to provide RSA and SEP with significant data in their attempt to answer the question: Will the array of existing services for the eduation and rehabilitation of the deaf-blind population currently being served by the centers and services program for deaf-blind children be able to meet the needs of that population as they reach adulthood? Being the federal agencies now responsible for providing educational and rehabilitation services to deaf-blind children and adults, RSA and SEP have questioned the adequacy of their resources to provide for this severely disabled group. Of particular concern are the young people born deaf-blind as a result of the rubella epidemic that raged in this country from 1963 to 1965. The potential impact of this group on service delivery can be illustrated by the fact that the average number of new clients each year from 1986-1988 needing adult services will be over 500 persons---nearly two and one half times the number who would usually be expected to become age-eligible for rehabilitation services, assuming the services are not initiated until age 21 (Dantona, 1981). While there have been deaf-blind persons requiring a variety of resources in the past, never have their numbers been so great nor their handicaps so extensive. This is a population that has such a broad spectrum of educational, work, and daily-care needs that special medical, social service, transportation, recreational, and other support systems will be required throughout their lives. In all of these areas there appears to be a need for an objective analysis of the services that exist in relation to the number and nature of the handicapping conditions of the deaf-blind population.

The contracting agencies specified six major objectives for this project; they are:

1. To provide information on the demographic nature of the deaf-blind population.

2. To identify the array of services, public and private, currently available for the deaf-blind population.

3. To determine the adequacy of available services and the present and future service needs of the deaf-blind population.

4. To specify the multiple resources required to meet the educational and rehabilitational needs of deaf-blind persons.

5. To outline a complete continuum of program options to meet the lifetime needs of the deaf-blind population and their families.

6. To develop plans for the dissemination of the study's findings and implementation of its recommendations.

This needs assessment has been designed as both an evaluation and planning study. The assessment has addressed current service systems from a variety of points of view: government officials, multi-state and single-state centers for deaf-blind children, the Helen Keller National Center and regional offices, State and regional offices of special education and rehabilitation, ESEA Title VI-C and non VI-C funded programs, national organizations, parents of deaf-blind persons, and deaf-blind individuals. The assessment has been accomplished through a series of tasks which included:

Task 1: Establish an advisory committee made up of consumers, experts, representatives of private and public organizations that serve deaf-blind persons, and Federal and State government program administrators, to assist in the development of data collection instruments and to review project findings.

Task 2: Develop an orientation to the study to familiarize staff with the full scope of RSA and SEP programs for the deaf-blind and to develop a comprehensive understanding of objectives and how they can be effectively met.

Task 3: Develop a conceptual framework of service delivery to deaf-deaf-blind individuals by which all services can be assessed.

Task 4: Develop a survey methodology and plan to submit it to the Office of Management and Budget for clearance.

Task 5: Collect data for assessment of services through direct face-to-face interviews and by mail.

Task 6: Analyze data collected in the previous step to (1) present a demographic profile, (2) identify services presently available, and (3) test the adequacy of services currently available and identify gaps which remain.

Task 7: Prepare a report on the policy implications from the assessment and a management plan for implementing findings.

Task 8: Prepare a final report which describes and presents the results of all project activities.

Task 9: Conduct an evaluation utilization seminar bringing together Federal and State program officials and public and private service providers to obtain their expert judgements as they relate to the following results of the study: policy implications of the findings, recommendations, plans for implementation of changes and areas of further research and evaluation.

The Needs Assessment of Services to Deaf-Blind Individuals project has identified strengths and weaknesses of current programs providing services to deaf-blind children, youth and adults. It has developed program policy options for the Rehabilitation Services Administratopm and Special Education Programs which may be used to improve their national programs by:

* providing systematic feedback from service providers;
* developing a prototype model for the current and future assessment of services to deaf-blind individuals; and
* improving the management and administration of service programs by identifying excesses and gaps.

Chapter III

Description of the Deaf-Blind Population

For purposes of the "Needs Assessment of Services to Deaf-Blind Individuals" study the target population was defined as those identified deaf-blind persons included on the registers of the Regional and Single State Centers for Services to Deaf-Blind Children and the Helen Keller National Center for Deaf Blind Youth and Adults. The definition used by the Regional Centers, for which the legal basis is contained in P.L. 91-230, Title VI, Part C, Section 622, is:

> ...children who have auditory and visual handicaps, the combination of which causes such severe communication and other developmental and educational problems that they cannot properly be accommodated in special education programs solely for the hearing handicapped child or for the visually handicapped (Federal Register, 40(35), February 20, 1975).

The Helen Keller National Center, for which legal basis can be found in Section 313 of Title III of the Rehabilitation Act of 1973 uses a different, more specific definition:

> Central visual acuity of 20/200 or less in the better eye with corrective lenses or central acuity of 20/200 if there is a field defect such that the peripheral diameter of visual field subtends an angular distance no greater than 20 degrees, and a chronic hearing impairment so severe that most speech cannot be understood with optimum amplification, and the combination of the two causes extreme difficulty for the person to attain independence in activities of daily living, psycho-social adjustment or in the pursuit of a vocational objective.

In the case of children's programs the federal definition was used where funding was provided through the VI-C centers. However, during the familiarization study included in this project, it was found that many programs, particularly those not receiving funds via VI-C, used other definitions. These included a combination of State standards for both vision and hearing loss, total vision and hearing loss, functional definitions, etc. Some of these programs did not realize that there was a federal definition. It was noted that variation in definition caused some problems when students were transferred across programs or when they were not found to meet the more rigid standards required for rehabilitation services.

One obvious finding is that deaf-blind persons are far from a homogeneous group. Not only do they differ greatly in terms of their sensory abilities but in terms of presence of additional handicapping conditions, level of intelligence, communication abilities, etc. The simultaneous absence or severe impairment of hearing and vision is recognized as one of the most limiting of all human disabilities. Waterhouse (1957) points out that in deaf-blindness, the resulting compound disability is different from and greater than the sum of the component disabilities. "The presence of a second handicapping condition does not add to a handicapped person's problems, it multiplies them" (Schein, 1978, page 4).

Fortunately, the total absence of both hearing and vision is very rare. Most persons considered to be deaf-blind have severe problems seeing and hearing, but they usually have some residual functioning in one or both modalities. Also, it is common for the onset of each loss to occur at different times so that there are at least two groups: deafened blind people and blinded deaf people. It has been suggested that there are four general groupings into which deaf-blind persons can be catagorized: (1) the person who has been both deaf and blind from birth or early childhood, (2) the person who has been blind from birth or early childhood and loses his hearing as an adult, (3) the person who has been deaf from birth or early childhood and loses his sight in adult life, and (4) the person who loses both sight and hearing in adult life. (Dinsmore, 1959, p.8). Each of these groups will have somewhat different service needs.

The degree of visual and auditory impairment in many congenitally deaf-blind children may be hard to ascertain. The questions of specific intellectual level and potential are compounded by extreme communication problems which preclude these children's ability to respond to their full capacity. Many of the children also exhibit extreme degrees of behavior problems, including autistic-type behaviors, such as lack of affect, social withdrawal, inability or disinclination to relate to others, self-abuse, self-stimulation, and perseveration (Robbins & Stenquist, 1967; Van Dijk, 1968; Guldager, 1970; Chess, Korn, & Fernandez, 1971; Kates, Schein, & Wolf, 1981).

Throughout the literature, communication is identified as the greatest problem facing any deaf-blind person. (Committee on Services for the Deaf-Blind, 1957; Keane, 1957; Industrial Home for the blind, 1959; Dinsmore, 1959; Sculthorpe, 1961; Salmon & Rusalem, 1966; Jensema, 1979a; Kates & Schein, 1980.) Because of the barriers imposed, deaf-blind persons are usually isolated and are often excluded from activities which are occurring in their environment.

Size and Characteristics of the Deaf-Blind Population

As the preceding discussion makes clear, deaf-blindness has been defined in a number of different ways. Rather than choose one definition and exclude information from all other sources, we have elected to provide estimates based upon four complementary definitions: These definitions range from a very limited category in which neither vision nor hearing is useful, to a rather broad category in which both senses, while severely impaired, provide some usefulness to the individual. The former group appears to approximate the adult population that HKNC is currently registering. The latter group reflects the thinking underlying the Congressional mandate; i.e., the simultaneous presence of both disorders makes futile educational efforts designed for students having only one or the other disability. The four categories are defined so as to fit the coding of the National Center for Health Statistics. (For details about NCHS's procedures and the techniques used to merge data for this analysis, see Chapter V.) The categories used in this study are:

Deaf-Blind = those persons having no usable hearing for speech and so severely impaired visually that they cannot read ordinary newsprint, even with glasses, or otherwise have visual defects to the extent that they have no useful vision in each eye.

Deaf and Severely Impaired Visually = those persons having no usable hearing for speech and who are severely visually impaired (but not blind) in both eyes.

Severely Impaired Auditorily and Blind = those persons whose better ear has a severe hearing impairment with the other ear equally impaired or worse (may be deaf) and blind, as defined above.

Severely Impaired Auditorily and Visually = those persons whose visual impairment is as defined in the second definition and whose auditory impairment is as defined in the third definition.

Data for the four categories defined above are presented in Table 3.1. Note that the categories are mutually exclusive. If one elects the fourth definition (severely impaired auditorily and visually), then the associated prevalence would be 734,275, since that category would in practice include the preceding three categories. The prevalence for any one category shows only the number meeting those criteria and not the others.

Table 3.1
Prevalence and Prevalence Rates for Four Categories of Deaf-Blindness in the Civilian, Noninstitutionalized Population of the United States

Category	Prevalence	Prevalence per 100,000
All Categories	734,275	346
Deaf-Blind	41,859	20
Deaf and Severely Impaired Visually	25,481	12
Blind and Severly Impaired Auditorily	357,818	169
Severely Impaired Auditorily and Visually	309,117	146

Sex. Females are represented in each group at a higher rate than males. The female preference may be attributed to the tendency of females to live longer than males and thus to become heir, more frequently, to degenerative conditions associated with aging.

Age. The highest prevalence rate in each of the categories is for the 65-and-over age group. The relationship between age and impairment has been demonstrated in most investigations of physical and sensory disabilities. Those individuals who have no impairments while young tend to develop them in later years; minor impairments in youth tend to become major impairments in old age.

Geography. Prevalence rates for all categories, except deaf-blind are highest in the South. In instances the lowest rates are in the North Central region. The West has lower rates than the Northest, except for the broadest definition and the overall rate. The four regions are those defined by the Bureau of the Census. Table 3.2 shows the great disparities between the prevalence rates for the regions. This finding does not hold for deafness alone, a condition whose prevalence rate was highest in the North Central area and lowest in the Northeast (Schein & Delk, 1974). Note that the South has nearly double the rates for the other regions in the category Blind and Severely Impaired Auditorily. The great discrepancies in these geographical rates deserve close scrutiny, because it may uncover etiological factors of significance to prevention.

Table 3.2
Prevalences per 100,000 for Four Categories of Deaf-Blindness, by Geographic Region

Category	Northeast	North Central	South	West
All Categories	288	285	464	298
Deaf-Blind	32	6	22	21
Deaf and Severely Impaired Visually	15	3	22	5
Severely Impaired Auditorily and Blind	130	134	252	119
Severely Impaired Auditorily and Visually	112	141	169	154

Institutionalized Population. The prevalences and prevalence rates for the four categories of deaf-blindness among the institutionalized population are shown in Table 3.3. The estimates can be directly compared to those in Tables 3.1 and 3.2, as the same definitions are used in each.

Table 3.3
Prevalences and Prevalence Rates for Four Categories of Deaf-Blindness in the Institutionalized Population of the United States

Category	Prevalence	Prevalence per 100,000
All Categories	13,182	754
Deaf-Blind	3,451	198
Deaf and Severely Impaired Visually	442	25
Blind and Severely Impaired Auditorily	1,548	89
Severely Impaired Visually and Auditorily	7,741	443

Sex. As with the noninstitutionalized population, females are represented at a higher rate than are males in the institutionalized deaf-blind population. The same explanation for the disparity in rates for the two sexes, longevity, would seem to apply here.

Age. Approximately 2 out of 3 deaf-blind persons resident in institutions are 65 years of age and older. Less than 8 percent of those in Table 3.3 are below 17 years of age.

Type of Institution. The majority of institutionalized deaf-blind persons are housed in nursing and personal-care homes (83.9 percent), with custodial institutions representing 7.2 percent, and long-term medical-care facilities the remaining 9.9 percent.

Institutional vs. Noninstitutionalized Populations. The overall rate for deaf-blindness is higher in the institutionalized than in the noninstitutionalized population. The prevalence rate for all categories is 754 per 100,000 in the former and 346 per 100,000 in the latter. This finding is consistent with most studies of physical and sensory impairments.

Chapter IV

Descriptions of Programs Serving the Deaf-Blind Population

Information relative to this topic was gathered during the familiarization phase. It included results of interviews with federal officials, representatives of the Helen Keller National Center, Directors of Title VI-C regional and single-state centers, staff from eight children's programs receiving support from the VI-C centers and six programs that were not, and state administrators for VR and special education.

Interviews with federal program officials. None of the programs administered by the 20 federal officials interviewed were direct service programs. Rather, they provided indirect services via funding of model projects, research or training of personnel. Seventeen of the officials reported that their programs are administered through the letting and monitoring of contracts or grants. The remaining three officials indicated they administered federal policy to states and monitored programs through regional offices.

Interviews with Director and regional representatives of the Helen Keller National Center for Deaf-Blind Youth and Adults. The Helen Keller National Center(HKNC) was authorized by Section 313, Title II, of the Rehabilitation Act of 1973, as amended, to operate as a national center and regional offices to assist State and local agencies in serving deaf-blind persons. HKNC is funded for its operation annually by Congressional appropriation. The regional offices are under the direct governance of the National Center in Sands Point, New York.

HKNC has as its mission to provide: (a) initial assessment of physical and psychological functioning to determine feasibility for admission to the comprehensive training program at the Sands Point facility or other programs; (b) multidisciplinary evaluation to determine individual rehabilitation needs, interests, and potentials; (c) individualized rehabilitation training; (d) training for new and prospective specialists; (e) community education; (f) development of a national register; (g) assistance to agencies to develop services for deaf-blind persons in their local communities; and (i) innovation and improvement of approaches and techniques of rehabilitation that will best contribute to the well being of the deaf-blind person. HKNC conducts research into the implications of deaf-blindness and is involved in designing and/or improving sensory aids that will reduce the handicapping effects of deaf-blindness. The regional representatives stated that their mission was primarily one of advocacy, casefinding, assessment, counseling, communication and employment assistance. The service to be provided will vary according to the needs of the deaf-blind client.

Staff at the National Center consists of approximately 40 persons including instructors, assistant instructors, instructor aides, rehabilitation counselors, social workers, audiologist, speech pathologist, psychologist, placement specialist, health care personnel and interpreters. Regional offices consist solely of the regional representative and a part time secretary.

According to their 1981 annual report 693 clients received some type of service between March 1, 1980 and February 28, 1981. Of these 130 were served by headquarter's personnel. Of major interest to HKNC is the designing and improvement of sensory devices. They are presently involved with testing of a Tactile Vibrator. HKNC works closely with numerous agencies serving the blind, deaf, and other handicapping conditions. Some of these include: (a) general rehabilitation agencies, (b) schools for the deaf, (c) schools for the blind, (d) Centers on Deafness, (e) State Services for the Blind, (f) Community Mental Health Centers, (g) nursing homes and (h) Community College programs.

Interviews with Directors of Centers and Services to Deaf-Blind Children programs. The two regional programs visited were the Mid-Atlantic-North and Caribbean Regional Center in New York City and the Mountain Plains Regional Center in Denver, Colorado. Single states included Colorado and Pennsylvania. The single-state centers are operated under the governance of their State Department of Education, the Mountain Plains center is a nonprofit corporation with a Board of Directors and the Mid-Atlantic center is operated under the auspices of the New York Institute for the Education of the Blind. A list of services provided by these centers appears in Table 4.2. Basically, their functions appear to be primarily administrative and supportive. As a group they provide an information network for each other and other persons interested in information and material on deaf-blindness.

The Centers provide service to children from birth through 21 years of age. Of the group visited, the population served ranges from approximately 120 students in Colorado to 836 in the Mid-Atlantic Region. Because their functions include such areas as media services, inservice training, provision of technical assistance and parent services the Centers also serve large numbers of adults. As with governance, the way in which service is delivered and staffing patterns vary. Some Centers maintain inhouse staff who provide service state or regionwide; others have minimal central office personnel and contract services directly to the States.

Interviews with eight programs receiving support from VI-C funded Centers. The sites visited were the Beatrice State Developmental Center, in Beatrice, Nebraska; the Colorado School for the Deaf and the Blind, in Colorado Springs, Colorado; the Industrial Home for the Blind, Children's Center, Brooklyn, New York; the Jefferson County Community Center for Developmental Disabilities, Arvada, Colorado; the Nebraska School for the Deaf, Omaha, Nebraska; the New York Institute for the Education of the Blind, Bronx, New York; the Overbrook School for the Blind, Philadelphia, Pennsylvania; and the Western Pennsylvania School for Blind Children, Pittsburgh, Pennsylvania. The governances of these programs differ. Several are part of a state-operated system (housed in state schools for the deaf or a developmental center), others are located in private schools or agencies. These programs are all responsible for direct services to children. Table 4.1 lists the specific services available. They vary greatly depending on the age and needs of the students and the resources of the program. The number of deaf-blind children served in these programs ranged from five to 85. In one program some of the children are categorized as mentally retarded and their deafness and blindness are considered secondary handicaps. Because of the variation in abilities of the students many different communication methods are taught, and there is varying emphasis on what would be considered prevocational and vocational areas.

These programs have relations with a number of other agencies, including: local education agencies, other schools for the deaf and/or blind, medical centers, hospitals, offices for persons with visual handicaps or communication disorders, community colleges and local universities, associations for the deaf or blind, mental health centers, foster-care agencies, and federal employment guidance services. All of the programs worked with their state or regional center and two were in contact with HKNC through its regional representatives. These relations were generally described as good.

Six of the eight programs stated that their present population was more disabled than that served in the past. This was attributed to admittance of children formerly excluded from school because their handicaps were too severe, children with better skills being placed in less restrictive environments than a class strictly for the deaf-blind, and a larger number of children with additional handicaps as well as severe behavioral disorders.

Interviews with staff of six non-VI-C funded programs. The sites visited for this part of the familiarization visit included; Madison Metropolitan School District, Memorial High School, Madison, Wisconsin, Meyer Children's Rehabilitation Institute, Omaha, Nebraska, Public Schools of the District of Columbia, Tyler Vision Program, Washington, D.C., Royer-Greaves School for the Blind, Paoli, Pennsylvania, United Cerebral Palsy of New York State, Carl Warner Center, Staten Island, New York, and United Cerebral Palsy of New York State, Project PLAY, New York, New York. The governance of these programs included State and local school districts, private schools and nonprofit agencies. Some of the arrangements are complex such as the United Cerebral Palsy of New York State which has contracts with the State Office of Mental Retardation and Developmental Disabilities to operate a program in a public institution as well as community living centers for post-institutional placements. In other instances, school districts provide day programs for children living in State institutions as well as children living at home. A State facility, Meyer Children's Rehabilitation Institute, is contracted by individual school districts to serve deaf-blind children. Royer-Greaves, a State approved private school, is reimbursed by the State and school districts to provide educational programming and residential care to multiply handicapped blind children and youths. None of these programs were administered by a agency specific to the deaf-blind population. The list of available services appears in Table 4.1.

As with the eight VI-C programs above these programs were currently serving more disabled children than they had in the past. Their populations had severe mobility and communication problems. One program did not consider its efforts to be "special education," because its population was so severely retarded.

Interviews with State agencies for rehabilitation and education. The interviews were held in Connecticut, the District of Columbia, and New York State. As with direct-service programs major differences in administrative structures and in service-delivery models were revealed.

In New York State, the Department of Special Education (DSE) and the Office of Vocational Rehabilitation (OVR) are both agencies of the State Department of Education. This administrative arrangement allows good interagency communication and coordination without special agreements. The DSE is responsible for educational and other related services to exceptional children and youth from the age of five to 21 years. Deaf-blindness is defined as a combination of deafness (=80 dB hearing level) and legal blindness, a definition more stringent than the federal definition. New York State has two major programs which serve deaf-blind children. These are the New York State School for the Blind, in Batavia, and New York Institute for the Education of the Blind, in the Bronx. A total of 10 programs provide service to 490 deaf-blind students in the State. All of these programs are funded in part or receive support services from the Mid-Atlantic Regional Center. Students who remain in educational programs until the age of 21 may be provided support services through OVR; when they leave the educational system, they are transferred to the Commission for the Blind, since that is the agency responsible for legally blind adults.

Deaf-blind children under 30 months of age only receive service from DSE on a special-needs basis. From 31 months to four years of age, deaf-blind children are under the auspices of the Family Court. The DSE encourages and supports a program of staff training and development in conjunction with Special Education Resource Centers and through tuition remission for professionals and paraprofessionals.

OVR provides services to deaf-blind individuals over the age of 18 years who are not in an educational program. The services provided include employment, vocational assessment, interpreter services, prosthetic devices and other related services as determined by the counselor who is the case manager. Family support services are provided if such services contribute to client welfare. Transportation is funded, if it is adjunct to training. The needs of the State's deaf-blind population as seen by the OVR and DSE administrators appear in Table 4.10.

In Connecticut one agency is responsible for services to deaf-blind individuals. This agency is the Board of Education and Services for the Blind. The Connecticut State Department of Education, Bureau of Student Services has the responsibility of assuring that programs exist and that program development takes place, but it only provides monitoring. The Board of Education and Services for the Blind is responsible for educational, vocational and other related services to deaf-blind individuals from birth through adulthood. Between 60 and 70 deaf-blind students and clients are served by the Board yearly. Currently, the age range of the individuals served is 8 years to 24 years. The Board's casefinding program enlists the assistance of the mental retardation facilities, school systems, the State Department of Education, the New England Regional Center for Services to Deaf-Blind Children, and preschool programs for the visually impaired.

Services provided through the board include: public and private education, various therapies (speech and language, movement, play, behavioral, physical, etc.), prevocational training, a sheltered workshop, employment counseling and referral, recreational services, alternative living arrangements, and family support services. The Board supports a work-activity center at the Oak Hill School and day treatment programs. Transportation is paid for in conjunction with going to and from a training or educational program. Consultation and financial assistance is also provided for general health care as needed.

In the District of Columbia, the Board of Education functions as both a Local and State Education Agency. The Division of Special Education is therefore directly responsible for educational and other related services for all handicapped children including the deaf-blind. At the time of the interview 36 deaf-blind students were being provided services. Partial support is provided for the program through the resources of the South Atlantic Regional Center for Services to Deaf-Blind Children. Students who are maintained in educational programs until the age of 21 may be provided with support services through the Department of Vocational Rehabilitation (DVR) when they reach 15.5 years of age. In contrast to New York and Connecticut, the District's education and rehabilitation programs are in separate agencies. The DVR is in the Department of Human Resources. There has been a formal agreement between the Division of Special Education and the Division of Vocational Education of the Board of Education and the Department of Vocational Rehabilitation since 1979.

Only evaluation services are provided by DVR at this time. Special education provides a full range of services including diagnosis and evaluation, special education, physical education, special therapies (psychopharmacology, dietary, speech/language, movement, play, behavioral, music, art, aquatics and horseback riding), general health care, dental care, vocational rehabilitation (including activity centers and vocational evaluation), recreation (after school, evening, day camp and trips, and summer camp), family support and staff training and development. Some of these services are available because of the location of the program in a building adjacent to a school for orthopedically and other health impaired children.

Type and extent of services provided. The age of the person being served and mission of the facility were found to be the most important factors in provision of services according to findings during the familiarization visits made by staff to various programs including eight children's programs funded under Title VI-C, six programs for children not covered by VI-C funding, two regional and two single-state centers for deaf-blind children and the Helen Keller National Center. Table 4.1 lists the services available in service programs for children as stated by personnel interviewed at the facilities.

Table 4.1
Services Listed by Personnel as Being Available to Children at Eight Programs Receiving VI-C Funding and Six Programs not Receiving VI-C Funding at the Present Time.

Services Listed as Available	VI-C (N=8)	Non VI-C(N=6)
Early intervention	2	0
General health care	4	2
Dental care	1	0
Visual testing	3	0
Hearing testing	3	1
Social service/family worker	3	0
Counseling	1	0
Psychologist	3	0
Special education	8	4
Feeding skills	0	1
Mobility	3	3
Recreation	3	1
Dietary therapy	1	0
Speech/language therapy	6	1
Sign language	6	5
Physical therapy	4	2
Occupational therapy	3	2
Movement therapy	1	0
Behavioral therapy	0	1
Music therapy	3	1
Art therapy	1	0
Physical education	4	0
Home living skills	2	1
Horticulture	1	0
Swimming	0	1
Computer training	0	1
Prevocational training	7	1
Sheltered workshop	1	0

Since these responses only represent 14 programs, they may not be representative of all such programs in the United States. However, they do illustrate the range of services that programs have found useful and presently provide to their deaf-blind students.

The next table (4.2) displays the services provided through the VI-C administrative units; that is, the services that the regional and single-state centers make available to the various educational programs in their jurisdictions. As would be expected, this list differs greatly from that of the direct-service providers. The information that is shown in Table 4.2 represents only the responses from two regional and two single-state centers. As noted above with regard to the educational programs, these four agencies may or may not be fully representative of the remaining agencies. The data do, however, serve to show differences in the characteristics of the two agencies.

Table 4.2
Services Provided by Regional and Single-State Centers for Services to Deaf-Blind Children

Services Provided	Regional	Single State
Coordinate and develop proposals	2	2
Dispense funds to SEA programs	2	1
Diagnosis and evaluation	2	1
Related service supports	2	2
Developing new concept models	1	1
Training of personnel	2	1
Parent awareness and training	2	1
Developing intervention models	1	1
Program evaluation	0	1
Coordination of services	0	1
Interagency service development across disability groups	1	1
Referral to other agencies	0	1
Consultation to SEA's	1	1
Media services	1	0
Maintain registry	2	1
Periodic surveys	1	1
Consultation in development of IEP's	1	1
Curriculum development	0	1
Monitoring programs	0	1

According to this information none of the centers were providing direct service to children. Their function was primarily that of support to programs, personnel and parents.

Interviews were held with the Helen Keller National Center's staff, in Sands Point, New York, and with two regional representatives of HKNC in Colorado and Pennsylvania. As with the children's programs the missions of the headquarters and the field service groups vary. The regional offices assist state and local agencies in serving deaf-blind persons in their home communities as well as referring them to the national center. Among the roles listed by the field persons were casefinding, assessment, advocacy (persuading other agencies to work with the deaf-blind person), counseling, employment assistance, assisting the elderly and general communication about the disability of deaf-blindness to the community and potential employers as well as to families.

HKNC has certain functions specified according to objectives mandated by Congress, when the Center was established. These include:

- Initial assessment of physical and psychosocial functioning to determine feasibility for admission to the HKNC or other agencies

- Multidisciplinary evaluation to determine rehabilitation needs, interests and potentials
- Individualized rehabilitation training
- Training for new and prospective specialists in services for deaf-blind persons
- Community education to sensitize both the lay and professional communities to the special needs of the deaf-blind person
- Identification and location of deaf-blind persons in order to develop a national register
- Encouragement of and cooperation in medical research into causes of deaf-blindness and methods of reducing or eliminating these causes
- Conducting research into implications of deaf-blindness
- Innovation and improvement of rehabilitation techniques
- Evaluation of effectiveness of services of HKNC
- Design and improvement of sensory aids, and
- Encouraging the development of services for deaf-blind persons by other private and public agencies.

In addition to the above the HKNC provides a wide variety of direct services to the clients who attend the Center. Among these are:

Arts and Crafts
Audiology
Communications Learning Center
Daily Living Skills
Home Management
Industrial Arts
Interpreter/Instructor
Low Vision
Medical
Orientation and Mobility
Placement
Psychology
Recreation
Rehabilitation Counseling
Social Services
Speech-Language Therapy

A program offering placement for qualified trainees in various levels of sheltered or competitive employment is also included in the total rehabilitation program. The three buildings that constitute the Center are newly constructed, using all specially designed features that are necessary for the trainee's accessibility, comfort, convenience, and safety. Services available to assist in community education include a library, publications, community education activities of the regional representatives, National Training Team, and volunteer services.

In all of the programs and facilities visited some mention was made of difficulties with communication. Because communication is an area of great concern for deaf-blind persons, some specific questions were asked of the programs visited about the use of various communication methods by students and staff. These were: (a) the type of communication used, (b) the proficieny of staff with these methods, and (c) whether the communication requirements were being met. Data on the first area is provided in Table 4.3 below. Responses to the other questions will be discussed under Adequacy of Services.

Table 4.3
Methods of Communication Used by Deaf-Blind Students in Fourteen Programs, by Type of Funding

Communication Methods Used	VI-C Facilities (N=8)	Non-VI-C Facilities (N=6)
Total Communication	4	1
Speech	4	3
Writing	1	0
Palm writing	1	0
Tactile clues	1	1
Physical manipulation	1	0
Speechreading	1	0
Communication boards	2	0
Photographs	0	1
Symbolics	0	1
Sign language	6	5
Gestures	3	2
Fingerspelling	1	0
Taste and smell	1	0
Handivoice (programmed recorder)	1	0

Adequacy of services. Items were addressed in the familiarization visits relative to adequacy of funding, facilities and services. The respondents included staff from direct service programs, children's center administrators and the Helen Keller National Center (central office and two regions). Responses regarding funding are shown in Table 4.4. The only group in which a wide majority stated they had been

Table 4.4
Administrator's Opinions of Adequacy of Their Funding, by Agency Type

	All (N=21)		VI-C (N=8)		Non VI-C (N=6)		Service (N=4)		HKNC (N=3)	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Has funding been adequate over the past 5 years?	16	5	6	2	4	2	3	1	3	0
Will funding for next 5 years be adequate?	2	15*	0	6*	2	2*	0	4	0	3

*Two VI-C and 2 non VI-C respondents said that they did not know.

satisfied with funding over the past five years were the programs that had received funding under the Title VI-C legislation. The other children's programs gave mixed responses with more agreeing they had been adequately funded. The HKNC group were unaminous in stating that their funding had not been adequate to do what they felt was necessary for deaf-blind adults.

The respondents presented a picture for the future that is almost totally negative; only two of 21 programs felt funding to support their programs would be adequate over the next five years. Various concerns were raised about availability and level of alternative funding that would be forthcoming with the demise of VI-C funds. A particularly worry was that if deaf-blind services were absorbed into more generic programs, such as those for the multiply handicapped or severely and profoundly retarded, the deaf-blind programs would lose their identity and with that the specialized services that deaf-blind children require. This would be particularly crucial in the areas of communication and mobility. No one thought that children would go unserved. The concern was that there be at least maintenance of the gains they had made in provision of services to the deaf-blind population and their families since the beginning of the program.

The next area addressed in the interviews with educational programs was adequacy of their facilities, including the quarters in which the programs are located, as well as the specialized furniture and equipment needed to conduct educational and therapeutic programs for deaf-blind individuals. The responses are shown in Table 4.5.

Table 4.5
Adequacy of Facilities Presently Available and Adequacy of Facilities for Future Students, as Judged by Administrators of Educational Programs, by Type of Funding

	VI-C Programs (N=8)		Non VI-C Programs (N=6)	
Judgment	Yes	No	Yes	No
Adequate for present populations	8	0	6	0
Adequate for future populations	1	5*	3	3

*Two respondents said they did not know

Staff at the programs visited felt that they had adequate facilities for their present populations. Some of these facilities had been acquired over a number of years and administrators spoke of the difficulties they had had obtaining their present space and how satisfied they now were. Their doubts about the future adequancey of their facilities were based on three factors: (a) the expectation that the incoming students would be more physically impaired than the present students, in which case the schools did not have appropriate space for wheelchairs or the necessary facilities for nonambulatory children---4 programs noted that they expected future students to be more disabled than those presently enrolled; (b) the expectation that the numbers of students will greatly increase in the next few years; and (c) the need for additional facilities and equipment for prevocational and vocational training, including simulated workshop areas.

Of the 14 programs which provide direct service to children, 9 were able to specify additional kinds of equipment and facilities they felt will be needed to do an adequate job in preparing their students academically and vocationally. Two programs felt they had adequate materials and two did not respond to this question. Table 4.6 lists the necessary additional equipment and facilities that would be helpful. Some of these items are also mentioned under communication, but here they are specifically related to education and rehabilitation activities in the schools.

Table 4.6
Equipment and Facilities That Administrators of 14 Educational Programs for Deaf-Blind Students Believe Are Needed But Not Presently Available or Adequate

Item	Frequency
Specialized space (e.g., for time out, recreation)	3
Adapted bathroom facilities	2
Improved communication boards (e.g., nonslip)	2
More space (unspecified)	2
Special tables and chairs	1
Better wheelchairs	1
Wheelchair access	1
Mobility equipment	1
Simulated workship areas	1
Living light center	1
Modified Language Master	1
Micro-switches	1
Biofeedback equipment	1
Audiometer	1
Soundproof room	1
Computerized instruction	1
Equipment for positioning	1
Sensory stimulation apparatus	1

Gaps in service delivery. Information gathered during the interviews reveals potential gaps in services or resources to meet the needs of the current and future deaf-blind population. Among the deficiencies are problems in the area of communication. Table 4.7 contains the administrators' estimates of the proficiencies of their staffs in communicating with deaf-blind students in their classrooms. What emerges from detailed questioning is that, although staff members for the most part can deal with primitive means of communication (such as gestures or physical manipulation of the child) or communication for which long-term and intensive training is not necessary (such as teaching students to use their sense of smell or touch), the staff members are not skilled in the more sophisticated procedures (such as fingerspelling or signing). The interviews revealed that manual communication is seldom part of the staff's communication repertoire.

Table 4.7
Administrators' Estimates of Staff Members' Proficiencies in Various Communication Methods Used by Deaf-Blind Students,* by Type of Funding

Number of methods with which staff are proficient*	VI-C Programs (N=7)**	Non VI-C Programs (N=6)
All	3	3
Most	1	2
Some	3	0
Few	0	2

* The list of methods appears in Table 4.3.
** One program did not respond

An additional inquiry was made regarding whether staff felt the communication needs of their student body were being met. Table 4.8 presents the results: less than half of the programs feel that all of their students' communication needs are being met.

Table 4.8
Administrators' Estimates of the Proportion of Deaf-Blind Students Whose Communication Needs Are Being Met in the Classroom, by Type of Funding

Proportion of Communication Needs Now Being Met	VI-C Programs (N=7)*	Non VI-C Programs (N=6)
All	3	2
Most	3	1
Some	1	1
Few	0	2

*One program did not respond

Pursuing this question further, the interviewers asked respondents in both VI-C and non VI-C programs whether there were any aspects of the communication teaching process that needed to be developed. Twelve of 13 administrators said yes. They gave many suggestions for aspects of communication that need further development. Their responses are shown in Table 4.9 .

Table 4.9
Administrators' Suggestions for Further Research Needed on Communication Aids for Deaf-Blind Persons

Suggestion for Needed Development	Frequency
Communication boards appropriate for the deaf-blind	5
Better auditory-training systems	3
Better amplification devices	2
Standardized system	1
Symbol system	1
More sophisticated nonvocal systems	1
Signal system to indicate Yes, No, etc.	1
Communication dictionary	1
Cause and effect toys and equipment	1
Micro-switch/biofeedback	1
Clearly specified communication assessments	1
Pre-linguistic inservice training	1
Communication services	1

A standardized system was described as some easily learned system that could be adoped nationwide for all severely handicapped deaf-blind children so that if they transferred from one program to another it would be possible for them to continue to make use of what they had already learned. It was noted that much of the communication equipment presently available was developed for children with the single handicap of deafness or blindness and therefore was not appropriate for persons who had the dual handicap of deafness and blindness. This would be the case with equipment such as communication boards which generally rely on the individual pointing out a particular picture, word or configuration based on visual discrimination. The respondents felt that some equivalent of this device should be developed for persons with a visual handicap. Also, it was clear that present amplification equipment needed improvement.

State-level administrators in Connecticut (CN), District of Columbia (DC), and New York (NY) were asked to rate the list of services shown in Table 4.10 according to the relative importance of each, using the following codes:

1 = Unimportant
2 = Moderately important
3 = Very important
4 = Essential

Table 4.10
Ratings of the Importance to Deaf-Blind Persons of Various Services by State-Level Administrators from Connecticut (CN), District of Columbia (DC), and New York (NY)

Type of Service for Deaf-Blind Person	Rating* CN	DC	NY
Early identification	4	4	4
Early intervention	4	4	4
Diagnosis and evaluation	4	4	4
Special Education	4	3	4
Physical Education	3	2	2
General health care	4	3	4
Dental care	3	3	3
Psychopharmacology	2	3	2
Nutrition	3	2	3
Speech and language therapy	4	4	4
Movement therapy	3	2	2
Play therapy	2	2	2
Behavioral therapy	2	3	3
Music therapy	2	2	2
Art therapy	2	2	2
Physical therapy	3	4	3
Occupational therapy	3	3	3
Day treatment program	3	2	2
Prevocational training	3	4	3
Activity center	3	4	4
Sheltered workshop	3	3	4
On-the-job training	3	2	3
Employment counseling and referral	3	3	4
Employment	3	2	4
Recreation programs	3	2	3
Respite care	3	3	4
Foster family care	3	3	3
Independent living with supervision	3	3	4
Residential care	3	2	4
Family counseling	3	3	3
Parent training	3	3	3
Homemaker services	2	3	3
Information and referral	4	3	3
Advocacy	3	3	3
Transportation	3	3	4
Financial planning	3	2	3
Staff training and development	3	3	4
Research:			
Biomedical	2	3	4
Behavioral	2	3	4
Treatment evaluation	2	3	4
Epidemiology	2	3	4
Psycholinguistic (communication)	2	3	4

*Code: 4 = essential; 3 = very important; 2 = moderately important; 1 = unimportant

It is worth calling attention to the finding that, with the exception of some of the less common therapies---movement, play, music, art---which usually are not available in any event, all services receive at least one rating of "very important". Some serices are regarded as essential by all three States: Early Identification, Early Intervention, Diagnosis and Evaluation, and Speech and Language Therapy. DC ranks Special Education "very important," while CN and NY consider it "essential." Other services rated "essential" or "very important" by all three States are: General Health Care, Physical Therapy, Occupational Therapy, Prevocational Training, Sheltered Workshops, Employment Counseling and Referral, Respite Care, Foster Family Care, Independent Living, Transportation, and Staff Development. New York was the most concerned about research activities. This is probably the area in which State departments of education and rehabilitation have least staff and resources. It is interesting to note that administrators rank Recreation much lower than do deaf-blind persons and their families. Another provocative finding is that the State-level administrators rate none of the services as "unimportant" to the well being of deaf-blind persons. This finding might be taken as one indication of these officials' opinions that the service gaps in education and rehabilitation of deaf-blind persons are very wide.

In addition to studying the resources required to meet the needs of the deaf-blind population via direct interviews and site visitations a special literature review was undertaken during the initial phases of the project. The search for relevant publications has continued through November, 1982. The review sought to uncover those documents which meet the following specifications: (a) containing information specifically relevant to the provision of services to deaf-blind persons, (b) including recommendations for services based upon the consensus of a significant number of participants in a conference or a survey that is of regional or national scope, and (c) has been published in and after 1974. The purposes of these specifications has been to assure that the material reviewed would be fairly representative of a broad range of potential viewpoints, rather than limited to some narrowly defined group of people, and that the opinions expressed would be fairly current and, therefore, likely to reflect the present state of affairs with respect to the needs and the provisions to meet the needs of deaf-blind persons.

Eight publications have been found to meet these criteria. Each is annotated in the immediately following pages. A further condensation of the material derived from these documents is presented at the end of the annotations in tabular form. Table 4.11 lists the recommendations extracted from these reports, indicating precisely where within each document the recommendations can be found. The purpose of this latter feature is to save the reader's time, should he or she wish to investigate further not only the exact wording used in the original publication, but also the nuances that may additionally explicate the intentions of the framers of the recommendations. The references in Table 4.11 are also referred to in Chapter VII, in which an effort has been made to bring together all of the various information from the interviews and surveys conducted for this report with the information gathered by prior studies.

[N.B.: Following each bibliographical entry is an abbreviation in parentheses. This abbreviation is then used throughout the report to identify the particular reference. The annotation describes sponsorship of the activity, its methods, and its participants. Conclusions relevant to this report will be found in Table 4.11, which follows immediately after the annotations.]

1. American Institutes for Research. Evaluability Assessment of the Deaf-Blind Centers and Services Program. September 1982 (AIR)

This report was prepared pursuant to Task Order 10 of Contract No. 300-80-0825- from the Division of Performance Management Systems, Organizational Performance Service, U.S.D.E. It presents the results of an evaluability assessment of the Deaf-Blind Centers and Services Program. Conclusions were based on document reviews and indepth interviews with program managers. Four regional centers were visited, 10 States responded to a SpecialNet survey and nine states to a telephone survey.

2. Boston College Division of Special Education and Rehabilitation. National Conference on Personnel Preparation in Deaf-Blind Multihandicapped Education. May 25-27, 1976 (BC)

This publication presents the proceedings and recommendations of a national conference held in 1976. It was attended by representatives of the Bureau of Education for the Handicapped, university personnel-preparation programs, regional centers, direct-service programs, and parents. The purpose was to discuss issues of major importance to the area of personnel preparation in deaf-blind education.

3. Project FORUM. Selected Issues in Service Delivery to Deaf-Blind Children. National Association of State Directors of Special Education, July 31, 1981 (FORUM)

This document was prepared in response to a request by the Office of Special Education regarding the delivery of services to deaf-blind children. A series of questions was posed to officials in 11 States, in order to determine the characteristics of the deaf-blind children currently being served, each State's system for delivery of service to the deaf-blind children, the part played by the VI-C centers in the children's education, and the areas in which the delivery of services to the deaf-blind children could be improved.

4. Management Services Associates, Inc. The Current Status of Prevocational Services for the Deaf-Blind Provided through the Regional Center Program. January 1976 (MSA)

This report was sponsored under Title VI-C, Section 622, ESEA (P.L. 91-230) Contract Number OEC-O-74-7930 RD. It was the result of a five-month study of 10 projects that had been awarded grants for planning and/or development of prevocational services for deaf-blind persons.

5. Hanley, Marilyn J. and Hanley, Dennis, E. Service Continuity for Deaf-Blind Children. The National Advocate, 9(3), 1981-1982 (NA)

This article presents the results obtained from a questionnaire mailed, in April 1982, to participants in a conference entitled, "The Deaf-Blind: Perceptions from the 70's---Directions for the 80's" that was held in December, 1981. The questionnaire asked for opinions about obstacles to the implementation of educational services for deaf-blind persons. Responses were obtained from 44 persons representing State coordinators of educational services for deaf-blind students, regional centers, and service providers.

6. Mid Atlantic North and Caribbean Regional Center for Services to Deaf-Blind Children. Proceedings: The 1980's, Partnerships in Planning for Progress. June 21-23, 1980 (MID)

The proceedings of a conference held to provide a forum for statements of present level of service, determination of needs, and specific recommendations for directions in services for the deaf-blind population in the 1980's. Participants included persons representing local, state, and federal education and rehabilitation agencies, medical and professional training centers, deaf-blind centers, direct service facilities, professional and parent groups, parents of deaf-blind persons and deaf-blind individuals.

7. John Tracy Clinic and South Central Regional Center for Service to Deaf-Blind Children. 1980 is NOW. A Conference on the Futures of Deaf-Blind Children. 1974 (NOW)

This conference was funded under the provisions of P.L. 91-230, Title VI-C ESEA/USOE. The purpose of the conference was to serve as a stimulus to prior planning to accommodate the maturing individuals within the deaf-blind population. There were approximately 30 persons in attendance, representing various agencies serving the deaf-blind population. Specific recommendations for future action were made.

8. World Council for the Welfare of the Blind. A Declaration of Rights of Deaf-Blind Persons. In: Proceedings of the First Historic Helen Keller World Conference on Services to Deaf-Blind Youths and Adults. Paris, France 1977 (RIGHTS)

This statement of rights of deaf-blind persons was unaminously adopted by delegates from 30 countries who attended the first international conference on services to deaf-blind youths and adults, in New York City, in September 1977.

Table 4.11
Recommendations Extracted from Eight Recent Documents* Reporting Studies of or Conferences on Services to Deaf-Blind People

Recommendation Made	References
1. Information needed about the size and characteristics of the deaf-blind population	AIR p.25, FORUM 1, NA 1.0, MID A-5
2. Clarification of definitions of deaf-blindness	AIR p.46, MSA p.7, MID A-2
3. Maintenance of register of deaf-blind persons	MSA p. 31, NA 1.b, MID B-10,17, NOW R-2
4. Dissemination of statistics on the deaf-blind population	AIR p. 45, MID A-4, B-18
5. Provide federal assistance to deaf-blind programs	AIR 1,3,4, FORUM 5, NA 2.3b, 3.1a, MID A-1, B-19 RIGHTS Art. 4
6. Provide federal allocations for special and support services beyond capability of states	AIR p. 24,25, NA 8.c, MID B-12
7. Funding to support educational/ vocational research	AIR 2, p.28, RIGHTS Art. 7
8. Funds to support preparation of personnel	AIR 2, p.26, B.C. 11, MSA p.30,39, NA 4.1, MID A-6,B-3,C-10,11
9. Coordinate planning between educational programs (IEP) and rehabilitation programs (IWRP)	AIR 4, MID A-10,11,12
10. Coordination of services to deaf-blind at a decision-making level in the State	FORUM 5, NA 3.0,3.1. 5.1a, MID B-2, NOW R-1
11. Develop model plans for centralized State coordination of life-time services for deaf-blind persons	MSA p.29,30,37, MID B-15,C-12, NOW R-3
12. Programming for parents	AIR p.26, FORUM 3, NA 4.1b, 7.1a, MID B-14

Table 4.11 (Continued)

Recommendation Made	References
13. Federal funds for respite care	MID B-8
14. Funds to educate parents about deaf-blindness	MID C-4
15. Establishment of hearing- and vision-conservation programs	BC 5, MID B-4, RIGHTS Art. 4
16. Development of curriculums on care of residual senses	BC B.3
17. An organized program of job training, job development and placement must be sponsored to supplement State resources	AIR 1, FORUM 3.5, MSA p.29, NA 5.1b,6.1d
18. Initiate special training for persons to be counselors for deaf-blind; inform them of client capabilities and motivate them to find jobs for clients	FORUM 5, MSA p. 29
19. Development of alternate-living programs including independent-living programs	FORUM 5, MSA p.32, NA 6.2b,6.c, MID B-9, C-13, NOW R-5, RIGHTS Art. 4
20. Research to overcome disadvantages of deaf-blindness	NA 6.2a, RIGHTS Art. 7
21. Research on communication of deaf-blind persons	MID B-3 RIGHTS Art. 7
22. Research on transportation for the deaf-blind population	MSA p.33
23. Federal support for recreational programs for deaf-blind persons	MSA p.36, MID B-9, RIGHTS Art. 8
24. Inclusion of consumers in decision making	MSA p.38, MID B-7
25. Conduct periodic surveys to determine trends in needs and accomplishments of deaf-blind persons	NA 1.2a
26. Extend age limit for educational services to deaf-blind persons	MSA p. 41, NA 2.1b, MID C-6

Chapter V

Methodology

The methodology for conducting this "Needs Assessment of Services to Deaf-Blind Individuals" involved a multifaceted approach. First, an Advisory committee was established to provide guidance to the project. Second, a series of familiarization activities took place including a thorough review of the literature, interviews with federal program officials and directors of public and private programs to determine what services were available to deaf-blind individuals and, third, a "Conceptual Framework for Services to Deaf-Blind Individuals" was developed. This framework covered the continuum of services prenatal through adulthood to guide the development of the data collection instruments and provide a framework for the analysis of data. Fourth, survey procedures were developed and implemented to collect the primary data used in this assessment.

Advisory Committee

A fourteen-member Advisory Committee was established. Members represent a variety of areas including consumers, private and public organizations that serve deaf-blind persons, and federal, regional, and state program administrators. The purpose of the Committee was, (a) to assist in the development of all data collection instruments, (b) to suggest which State agencies for vocational rehabilitation and special education should be visited during the familiarization phase of the project, and (c) to review the project's report. A list of committee members appears on the following page.

The Advisory Committee met twice in Washington, D.C. during the course of the project. Members were also contacted individually by telephone and mail at various times to keep them informed about the course of the project and to obtain their opinions. The Advisory Committee, while contributing to all phases of the project, contributed most heavily to the development of the Conceptual Framework, the items included in the data collection instruments, and the suggested policies and management options.

Familiarization Phase

The purpose of the familiarization phase was to allow staff to become thoroughly familiar with available services for deaf-blind individuals by (a) reviewing relevant literature, (b) interviewing Federal Program officials and (c) making visits to public and private service providers.

Literature review. The literature review included a study of available documents relating to legislation and administrative policies, proceedings and reports of conferences and surveys that had been published, testimony regarding needs of deaf-blind persons, materials developed by agencies and programs about their specific philosophies and practices and material provided by professional organizations and in professional books and journals. Over 400 references were found to be

NEEDS ASSESSMENT OF SERVICES TO DEAF-BLIND INDIVIDUALS

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of relevance to this project. An annotated bibliography of 55 references was incorporated in the Familiarization Report contained in the Monthly Report submitted January 31, 1982, to the Project Officer. This report also contained the details of testimony by 16 persons which was presented to the New York Senate Minority Task Force on Multi-handicapped Deaf Young Adults. Sources for the literature review were suggested by various bibliographies, conferences, and other activities conducted during the project.

Interviews with federal program officials. To gain an understanding of the services provided to deaf-blind persons by federal programs in selected agencies, interviews were conducted with the following persons: Dr. Paul Andereck, Education Specialist, Captioned Films and Media Applications, SEP; Dr. Richard Champion, Project Officer, Handicapped Children Early Education Program, SEP; Mr. Robert Dantona, Chief, Deaf-Blind Section, SEP; Dr. Allen Dittman, Education Research Specialist, Research Projects Branch, SEP; Dr. Norman Howe, Chief, Central Regions Branch, Division of Personnel Preparation, SEP; Dr. Malcolm Norwood, Chief, Captioned Films Program, SEP; Dr. Joseph Rosenstein, Acting Chief, Regional Educational Programs for the Deaf and Other Handicapped, SEP; Ms. Josephine Taylor, Chief, Education Programs, Division of Personnel Preparation, SEP; Mr. Paul Thompson, Chief, Special Needs Section, SEP; Ms. Edna Adler, Assistant Chief, Deafness and Communicative Disorders Branch, RSA; Ms. Elizabeth Arroyl, Chief, Independent Living Section, RSA; Dr. William Bean, Chairman, RSA System Task Force, RSA; Mr. Charles Freeman, Chief, Rehabilitation Branch, Division of the Blind, RSA; Ms. Toby Hollin, Training Specialist, Office of Development Programs, Division of Resource Development, RSA; Dr. Robert Winn, Director, Division of the Blind, RSA; Dr. L. Deno Reed, Director, Research Program Administration, NIHR; Ms. Eleanor Bader, Special Assistant to the Deputy Commissioner, Social Security Administration; Mr. Steve Cohen, Chief, Rehabilitation Programs Coordination Branch, Office of Disabilities, Social Security Administration; Mr. John Pride, Director, Division of Program Services, Administration of Developmental Disabilities, HHS; Ms. Madelyn Schultz, Program Analyst, Division of Program Development and Demonstration, Administration on Developmental Disabilities, HHS.

Interviews with public and private service providers. To assess what services were currently available through public and private service providers, interviews were conducted with the Director of the Helen Keller National Center for Deaf-Blind Youth and Adults (HKNC), the Regional Representatives of the HKNC Central Region and the Mountain Plains Region, the directors of two single-state and two multi-state Centers for Deaf-Blind Children, the administrators or coordinators of eight VI-C funded Regional/ Single State programs and six non VI-C funded programs, the directors of three state agencies for special education and the directors of three state agencies for vocational rehabilitation. The results of these 27 interviews are detailed in Chapter IV of this report.

Conceptual Framework. The purpose of this activity was to develop a model by which all services to deaf-blind persons could be assessed.

Using the Model State Plan for Rehabilitation of Deaf Clients (Schein, 1973) as a prototype, a conceptual model of services that addressed all major decisions affecting service delivery to deaf-blind persons was developed. The original model was modified to include educational services and broadened to cover elderly deaf-blind persons. In addition, the model was further expanded by information collected from the literature review and interviews with federal program officials and service providers. As a final check on the appropriateness and inclusiveness of decision points, the Advisory Committee reviewed the document and made pertinent recommendations.

Survey design and procedures. The survey design for this project entailed the collection of primary data from four respondent groups, in order to assess present service capacity and to identify service needs. The respondent groups were drawn from the following:

(a) the estimated 5,000 deaf-blind adults on the HKNC register;

(b) the parents of the 6,000 deaf-blind children on the registries of the Centers for Services to Deaf-Blind Children;

(c) the administrators of the 300 programs that provide services within the Centers for Services to Deaf-Blind Children;

(d) the estimated 2,000 teachers of deaf blind children.

The general sampling approach involved drawing stratified, random samples from each of four populations; (a) teachers of deaf-blind individuals, (b) administrators of service programs, (c) parents of deaf-blind persons and (d) deaf-blind adults 21 years of age and over. The Regional Centers for Services to Deaf-Blind Children and HKNC provided lists from which the samples were drawn. From the first three populations of teachers, administrators, and parents, random samples within each group were drawn from the following 10 multi-state and single-state Centers for Services to Deaf-Blind Children, comprising 43 states, three territories, and the District of Columbia.

A. Multi-state centers

1. New England (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont)

2. South Atlantic (District of Columbia, Maryland, North Carolina, South Carolina, Virginia, and West Virginia)

3. Mid-Atlantic (Delaware, New Jersey, New York, Puerto Rico, and the Virgin Islands)

4. South Central (Arkansas, Iowa, Louisiana, Missouri, and Oklahoma)

5. Southeast (Alabama, Florida, Georgia, Kentucky, Mississippi, and Tennessee)

6. Southwestern (Arizona, California, Guam, Hawaii, Nevada, and the Trust Territories)

7. Mountain Plains (Idaho, Kansas, Montana, Nebraska, New Mexico, North Dakota, Utah and Wyoming)

B. Single-state centers

1. Colorado

2. Pennsylvania

3. Texas

Each program in the 10 multi-state and single-state centers was asked to provide lists of their administrators who are currently employed. An administrator is defined as someone who makes decisions in some or all of the following categories: (a) selection and retention of personnel, (b) fiscal management, and (c) determination of policy. An administrator must also have direction and supervision of two or more professional individuals.

The administrators were placed in strata defined by (a) the size of the program and (b) the length of time the program had been in existence. The levels within these strata were determined empirically. The weightings for the draws was proportional to the individual cell frequencies. The stratification variables were selected, first, because they were continuous and as such were likely to provide programs of diverse structure, something that might be missed if categorical variables were selected, and, secondly, because the information was readily avaliable from the regional centers. The sample size for administrators was set at 36.

To avoid any possible conflict with the Privacy Act, names and addresses of teachers and parents were not requested directly. As with the sampling plan for administrators, each of the programs within the 10 multi-state and single-state centers was requested to provide unique identification numbers for their presently employed teachers of deaf-blind students. A teacher is defined as one who (a) has direct instructional contact with deaf-blind children for four or more hours per week, (b) bears primary responsibility for their instruction, (c) is qualified by degree training, and (d) is recognized by the institution as being a teacher. The teachers' numbers were assigned to strata defined by (a) the size of the program for deaf-blind children and (b) the length of time the program has been in existence. The sample size for teachers was set at 64.

Sampling plan for parents of deaf-blind children. Each of the programs in the 10 multi-state and single-state centers were requested to provide a listing that included unique student identification numbers and the age and sex of each student enrolled in the program. A parent of a deaf-blind student is defined as the natural parent or anyone who was the legal guardian of a deaf-blind child. A deaf-blind child is defined as any child listed on the register maintained by a Center for Services to Deaf-Blind Children. The students were stratified by (a) age and (b) sex. The schools were then instructed to send the questionnaires to the parents of the children whose identification numbers were drawn, with the limitation that only one parent per child could be used. The sample size for parents was 150.

The sample of deaf-blind adults was a two-stage, stratified random sample of persons listed on the HKNC register. Stage one limited the sample to persons 21 to 55 years of age, residing in 10 states (Alabama, California, Colorado, Kansas, Massachusetts, Missouri, New York, North Carolina, Pennsylvania, and Texas). The states were randomly selected from the 16 federal regions for services to deaf-blind children. The second stage limited the sample to those who had normal or better intelligence and who could communicate in any of the standard means of communication with deaf-blind individuals. HKNC overdrew the first stage, selecting 100 cases from the register. Information for each case was then obtained from the HKNC regional office staffs with respect to the second stage criteria. After the eliminations were made, a final sample of 50 cases meeting the survey criteria was selected. To foster cooperation and protect confidentiality, HKNC mailed a letter (or contacted directly) all potential cases, explaining the study and requesting their participation. REDEX received only the names and addresses of those individuals who agreed; therefore, a description of persons who may have been drawn and who refused to participate is not available. The number of refusals, however, is very small, being fewer than 10, and not likely to introduce any additional significant bias into the sample.

The questionnaires and interview schedules used in the four surveys were based upon the Conceptual Framework developed for this project. Draft questionnaires were pretested with program administrators, teachers, parents, and deaf-blind adults in Washington, D. C. and New York City. In addition, the questionnaires were reviewed by the Advisory Committee members and by various officials in the federal government and associated organizations, including CEIS, FEDAC, and OMB.

With the exception of the deaf-blind adult sample, information was gathered by mail questionnaire. Each program administrator received a packet containing a questionnaire for himself or herself and questionnaires he or she had agreed to mail to the teachers and parents drawn from that program. Identification numbers of the teachers and parents to be contacted were provided, along with covering letters, mailing envelopes to forward letters and questionnaires to the sample members, and stamped-REDEX-addressed return envelopes for the convenience of the respondents. Because the names and addresses of the teachers and parents were not known to REDEX, follow-up efforts had to be made through the administrators. These were done by mail and telephone to encourage administrators to contact teachers and parents.

Interviews with deaf-blind adults were conducted by the four principal members of the REDEX project team. Where necessary, interpreters skilled in communication with deaf-blind persons were employed. In most instances, however, the interviews were conducted solely by the staff members, using whatever forms of communication the deaf-blind adult shared with the staff member: visual or hand-on-hand signs, fingerspelling in the hand with the American One-Handed Alphabet, orally, or a combination of these.

Response Rates. Where direct contact with respondents was permitted, the response rates were high: 100 percent, for deaf-blind adults, and 92 percent (33 of 36), for administrators. The returns for parents amounted to 31.3 percent of the sample, and for teachers to 53 percent of the sample.

Secondary Data Bases. To estimate the size of the deaf-blind population, data from four sources were combined. For deaf-blind persons 0 to 21 years of age, information was provided by the Deaf-Blind Section of SEP. HKNC provided information on persons over 21 years of age listed on their register. For the civilian, noninstitutionalized population of the United States, the data came from the Health Interview Survey, National Center for Health Statistics (NCHS), and for the institutionalized population, from NCHS's Master Facility Inventory. The Health Interview Survey consists of weekly samples of the United States, drawn so as to accurately reflect the civilian, noninstitutionalized population. The survey is conducted by NCHS, the organization charged by Congress to provide "annual information on the Nation's health." Interviews are assigned to the Bureau of the Census; design and analysis are responsibilities of the NCHS staff, supported by experts in the field who assist with special problems. The Master Facility Inventory is based on a list of institutions throughout the United States, each of which completes a census of its residents (inmates, patients, etc.) that includes information about impairments that parallels that gathered by the Health Interview Survey.

A severe problem in combining the various data bases is the lack of uniform definitions. These problems have been discussed in detail (Schein & Delk, 1974). Using the statistical procedure adapted from Hansen, Hurwitz, & Madow (1953), estimates from the four sources were processed to yield the estimates presented in Chapter III. The definitions used are described in that section. For further detail about the NCHS definitions and coding strategies, see X Codes for Special Impairments by Site and Etiology, Revised January 13, 1969 (Department of Health, Education and Welfare, Public Health Service, National Center for Health Statistics, Division of Health Statistics.)

Data Processing. All data have been coded by REDEX staff members and reviewed by the project's principals. Any data inconsistencies were resolved by consensus of the principals. Computer entries have been verified by re-entry and by computer screening. Programming used has been validated by the developers with a high assurance of reliability. Test re-runs were made of a small sample of the data to confirm the accuracy of all aspects of the process. No errors have been detected in the data processing.

Chapter VI

Analysis of the Data

The results of the four surveys done for this report are presented in the first sections of this chapter, along with the principal analyses relating to each. The remaining portions of the report integrate the findings from the multiple sources of information and bring them to bear upon the definition of policies and management strategies that flow from the data that have been gathered. The latter sections also support the recommendations, where indicated, with references to the pertinent literature that presents the research and opinions of others who have undertaken an investigation of the problems of the deaf-blind population.

Administrators

The following analyses represent the replies of 33 Administrators actively involved in the education of deaf-blind children and youth. As an initial explicatory variable, the ages of the students under the purview of the respondents have been used. The small numbers involved, however, did not allow for more than a simple division into those students 12 years of age or younger and those 13 years of age and older. Aside from the relative cohesiveness of the two categories, the division also creates two fairly equal groups of 14 and 20, respectively for the Administrators of younger and older students. (Note that in one case, the same Administrator has responsibility for students in both age groups.

Description of the Student Sample: Administrators. The 585 students in programs administered by the Administrator sample had a substantial number of disabilities in addition to deafness and blindness. Table 6.1 shows the numbers reported to have various conditions. As the data make apparent, the deaf-blind students in these schools are severely disabled

Table 6.1
Number of Students in Programs Administered by Respondents in Administrator Sample, by Additional Disabling Condition and Age*

Additional Disabling Condition	12 Years and Under	13 Years and Over
Cerebral palsy	63	73
Emotional problems	24	33
Heart disorders	18	67
Mental retardation	165	309
Brain damage	112	214
Epilepsy	34	65
Orthopedic	91	61
Learning disabilities	56	54
Other	26	5

*Numbers cannot be added, as students may have more than one additional disabling condition.

by conditions in addition to their deaf-blindness. The predominating additional disabilities are mental retardation and brain damage. The latter designation, of course, could be correctly applied to all of the students, insofar as they are deaf and blind, both central-nervous-system disorders. Also, while cerebral palsy and epilepsy are listed separately, they should be considered as a refinement of the nondefinitive brain-damage category.

Educational Setting and Purview. Of the 33 programs represented, 15 cover the entire state in which they are located, 9 part of a state, 8 a metropolitan area, and 1 a region. Ten of the programs have no minimum age, 8 set a minimum age under five years, 7 at five years, and the remainder at various ages up to thirteen years. The maximum ages ranged from 13 to 29 years of age, with 20 at twenty-one years of age and 9 over that age.

Table 6.2 shows the settings in which the programs operate. The most frequently mentioned is the residential setting, with day schools a distant second. Note that a number of the administrators who responded have the responsibility for units in more than one setting. (See also "Physical Plant and Staff.")

Table 6.2
Distribution of Programs Administered by Respondents in Administrator Sample, by Type of Setting

Type of Setting	Number
All Settings	33
Custodial Institution	7
Residential School	18
Day School	9
Special Class	5
Resource Room	1
Itinerant	2
Mainstream	3
Other (including hospital)	4

Nine of the 33 administrators (about 1 in 4) believe that they are serving all of the deaf-blind persons in their purview. The remainder were asked to estimate the number of unserved deaf-blind children in their administrative area. The total estimate of eligible deaf-blind persons not in programs is 54, roughly 10 percent of those served by the responding programs. Of these 14 are in the younger age group and 40 in the older age group. The minority of programs (14) do conduct active searches for deaf-blind children and/or youth in their area. Of the 19 that do not, all but 2 cooperate with child-find activities of other agencies.

The Administrators generally regard their programs as being appropriate educational placements for the majority of their students.

Only 6 Administrators believe that they have students who would be better placed elsewhere. Of these, only 1 program is in the younger group and 5 in the older group. Altogether, just 21 students are involved: 7 in the younger group and 14 in the older group. The reasons given for misplacement are that the 7 younger students are too high-functioning and that all but one of the older students are too low-functioning.

Financing. Federal VI-C monies provide at least a part of the funding for 29 of the 33 programs; 8 spend other federal funds; 24 have state funds; 10 receive funds from a local education agency or coalition of local agencies; and 3 have private funds.

Almost without exception, the respondents have multiple funding sources. Their major source of funds is the state education department for 14 and VI-C for 8, with only one or two respondents indicating that any other source is predominant. Seven programs indicate that all of their support comes from earmarked funds and 2 that none of their support is from earmarked funds. The distribution appears in Table 6.3.

Table 6.3
Percent of Support Derived from Earmarked Funds by Administrator Respondents' Programs, by Age of Students in Program

Percent	12 Years and Under	13 Years and Over
All Programs*	14	20
None	1	1
1 - 25	4	3
26 - 50	0	4
51 - 74	1	0
75 - 99	0	5
100	5	3
Nonresponse	3	4

*One program that receives 100% of its support from earmarked funds has students in both age categories

The tabulations indicate that earmarked funds are more often depended upon by programs for younger than for older students, though the tendency is only a moderate one.

The Administrators tend to be pessimistic about their future support. Over the next four years, 19 believe it will be worse, 10 that it will remain about the same, and 1 that it will improve (3 did not respond). There is no significant difference in these predictions by the age of students served.

Diagnosis and Evaluation. Table 6.4 displays the responses of the Administrators to the questions about the average frequency of various types of examinations. Almost every program provides for periodic visual and auditory examinations. Most programs also assess academic achievement on a regular schedule. The examinations that appear to be most overlooked by the programs are prevocational and vocational. Vocational assessments of those under 13 years of age are not particularly appropriate, though prevocational examinations, broadly construed, would be. Of the 20 programs having students 13 years of age and older, 9 do not make any provisions for periodic vocational assessment, while 2 do so semiannually, 8 annually, and 1 biannually. In this same age group, prevocational examinations are given semiannually by 4, annually by 13, biannually by 1, and aperiodically or not at all by 2.

Table 6.4
Average Frequency with which Students Receive Various Examinations in Programs Administered by Respondents, by Students' Ages

	12 Years and Under					13 Years and Over				
Type of Examination	A	B	C	D	E	A	B	C	D	E
Visual	1	7	2	3	1	1	16	2	1	0
Auditory	1	8	3	2	0	1	13	5	1	0
Intelligence	0	2	4	5	3	1	4	6	6	3
General Physical	0	6	3	1	4	2	14	1	0	3
Academic Achievement	3	7	2	0	2	4	11	1	2	2
Speech and Language	4	8	1	0	1	3	13	2	1	1
Mobility	4	3	2	3	2	1	11	1	2	5
Self-Help Skills	6	6	1	0	1	5	13	1	1	0
General Behaviors	6	4	1	0	3	4	11	1	1	3
Prevocational	3	4	2	0	5	4	13	1	0	2
Vocational	2	2	1	3	6	2	8	1	0	9

A = semiannual or more often; B = annual; C = biannual; D = triennial; E = as needed or not at all.

The Administrators are generally satisfied with the various evaluations. All or almost all are satisfied with the visual and auditory testing, the general physical examinations, academic achievement testing, mobility evaluations, and self-help assessments. In the younger age, only 1 demurrer was registered and that was with regard to intelligence testing. In the older age group, 4 administrators expressed dissatisfaction with the visual examinations, 5 with intelligence testing, 3 with assessments of general behavior, 4 with the prevocational testing, and 2 with vocational evaluations. These data are summarized in Table 6.5.

With respect to assessment materials, the Administrators suggest that it would be desirable to have measures normed or adapted for very low-functioning deaf-blind students (6), better measures of intellectual functioning (3), and improved tests of language development (3). Overall, however, they remain unperturbed about assessment materials.

Curriculum and Instructional Aids. While the majority of Administrators are satisfied with present curricular materials, a strong minority are not. Four of the 14 who have younger students are not satisfied, as are not 9 of the 20 who have older students. The areas to

Table 6.5
Ratings of Satisfaction with Various Examinations by Administrators, by Age of Students

	12 Years and Under		13 Years and Over	
Type of Examination	Satisfied	Dissatis	Satisfied	Dissatis
Visual	14	0	16	4
Auditory	14	0	19	1
Intelligence	13	1	15	5
General Physical	14	0	20	0
Academic Achievement	14	0	19	1
Mobility	14	0	20	0
Self-Help Skills	14	0	19	1
General Behavior	14	0	17	3
Prevocational	14	0	16	4
Vocational	14	0	18	2

which the dissenters point are daily living skills (5), language development (4), vocational competence (4), and leisure-time activities (2). Instructional materials receive almost no criticism. Only 3 Administrators express any dissatisfaction with available materials.

Administrators report they have little specialized equipment for educating deaf-blind students, and they express little desire to own any of the presently available devices. Of the 28 Administrators who responded to the question about group aids, 18 report that they have none. The proportions having them are the same for the younger and older groups. Only 2 Administrators feel they would like to have group aids. A single Administrator of 28 reporting has a Kurzweil Reader. None indicate that they want one. Two Administrators say their programs have one or more Versabraille machines. None request one. The same holds true for the Portareader. However, while none of the Administrators presently have a Pelco Electronic Low Vision Aid, 4 say they would like to have one or more for their programs. Five Administrators' programs have one or more Visualtek R/S Systems, but none express a desire for more of this item for the remaining 23 programs. Optacons are owned by 5 programs, and 2 additional programs would like more of them. Five programs also have Tellatouch machines, and 2 programs would like to add them. Two programs have Vibralert systems, and 2 more would like to have them. No other equipment was indicated as owned or desired.

Physical Plant and Staff. Half of the Administrators find their physical facilities adequate (17): 13 want more space; 6 feel their plants need substantial and 8 moderate refurbishing. Twenty-two have dormitory facilities for their students. They board 379 students in facilities they regard as excellent in 6 instances, good 14, fair 1, and poor 1. The most desired improvements are for more space, in the one instance, and better designed space in the other.

The dormitory staffs are regarded as excellent by 6 Administrators, good by 13, fair by 2, and poor by 1. The three Administrators who rate their dormitory personnel fair or poor believe that better training and more staff will improve conditions. Excessive turnover is also noted as a problem they would like corrected. In response to a specific question about inservice training, the Administrators who rated their dormitory staffs as fair or poor all said such training would be desirable.

Faculty. Table 6.6 shows the distribution of the faculties of the Administrator respondents' schools. Nine Administrators did not provide this information in a form that could be used for this tabulation. For those who did, the data reveal a significant difference between the degree qualifications for those teaching younger vs. older students. Almost a third of the teachers of younger students have less than a bachelor's degree, while this is true for only 8 percent of those teaching the older students. Teachers of the younger students have bachelor's degrees at the rate of 36 percent and master's degrees 33 percent, compared to 48 and 44 percent for teachers of the older students. The staffs do not differ greatly by years of experience. The younger students' teachers average a bit more than 4 years in their programs, the older students' teachers a bit less than 4 years. The great difference, then, is in the degree qualifications of the two groups' faculties.

Table 6.6
Distribution of Degrees Held by Teachers in Programs Administered by Respondents, by Teachers' Years in Reporting Programs

Degree/Years of Experience	12 Years or Under	13 Years or Over
All degrees and years	55 (100%)	87 (100%)
Less than Bachelor's	17 (31%)	7 (8%)
1 or less	0	2
2 to 5	0	3
6 or more	17	2
Bachelor's	20 (36%)	42 (48%)
1 or less	1	6
2 to 5	16	33
6 or more	3	3
Master's	18 (33%)	38 (44%)
1 or less	3	2
2 to 5	13	12
6 or more	2	24

Supporting Staff. The Administrators' reports show that they have fairly limited numbers of specialists available on a full- or part-time basis. A breakdown of the number of supporting staff is given in Table 6.7, by type of professional. The figures represent 31 programs that provided usable information on this item. The remaining 3 programs did not reply or did not provide data in a form that could be tabulated.

Table 6.7
Number of Professionals Employed by Respondents' Programs, by Title and Employment Status and Age of Students

	12 Years and Under		13 Years and Over	
Title / Work Status:	Full-Time	Part-Time	Full-Time	Part-Time
Teaching Aides	54	17	83	18
Speech Pathologist	13	7	10	9
Physical Therapists	7	10	1	5
Movement Therapists	3	0	3	1
Occupational Therapists	8	9	2	7
Mobility Instructors	4	5	4	3
Social Workers	10	7	3	5
Prevocational/Vocational Teachers	9	1	7	4
Other (e.g., Music Therapist)	4	7	5	8

The Administrators' attitudes toward personnel are revealed in their responses to several questions posed to them. They are about evenly divided as to whether turnover is a problem. Sixteen check no problem, 13 a minor problem, and 5 a major problem. There is a tendency for the Administrators of programs for the older students to regard turnover as a problem (60 percent) more often than those for younger students (43 percent). With respect to training, 14 programs see preservice training as no problem, 12 regard it as a minor problem, and 7 as a major problem. Eleven do not believe that inservice training is a problem, while 18 see it as a minor and 2 as a major problem. Morale is considered a major problem by 4 Administrators, as a minor problem by 19, and as no problem by 10. Half of the Administrators of programs for younger students see this as no problem, while only 16 percent of those managing programs for older students agree with that sanguine picture. Salaries are thought to be no problem by 17 of the Administrators, a minor problem by 11, and a major problem by 6. All but one Administrator sees absenteeism as no problem (19) or a minor problem (13). Clearly, in the views of the Administrators, the two greatest problem areas are morale (23 of 33 see it as a problem) and inservice training (20 of 31 see it as a problem). The two least problem areas are absenteeism (19 saying it is no problem) and salaries (17 saying it is no problem).

Opinions of Deaf-Blind Adults' Problems: Administrators. The opinions of the Administrators about eight problems that may confront deaf-blind adults are shown in Table 6.8. The Administrators rated each of the eight on a four-point scale: none, mild, moderate, severe. Most agree that earning a living would be a severe problem (27 of 31), with no difference between Administrators of programs for younger versus older students. Obtaining attendant care is not viewed with the same degree of concern; only 12 of 31 considering the problem severe. Finding suitable living quarters is seen as less of a problem by the Administrators of younger students (4 of 13 say it is no problem) than by Administrators of older students (1 of 18 says it is no problem); overall, however, 25 of 31 regard it as a potentially moderate to severe problem. Obtaining higher or continuing education, in the view of Administrators of younger students, will be a moderate-severe problem for 8 and mild-none for 4; in the views of Administrators of older students, it will be a moderate-severe problem for 14 and mild-none for 3, suggesting that there is more concern among those who have older than those who have younger students to manage. Both groups of Administrators agree that recreation will likely be a difficult problem for their students when they become adults. Both groups of Administrators are about equally worried about transportation problems their students will face after graduation. Self care, while still seen as a moderate-severe potential problem by the majority of Administrators, rates as the least of the eight problem areas. Communication, on the other hand, is among the most provoking of the eight problems the Administrators have rated.

Table 6.8
Administrators' Ratings of Eight Potential Problems Deaf-Blind Adults May Confront, Age of Students Respondents Are Managing

	12 Years and Under				13 Years and Over			
Problem Rating:*	No	Mi	Md	Sv	No	Mi	Md	Sv
Earning a living	2	0	1	10	0	1	0	17
Obtaining attendant care	3	0	6	4	3	1	6	8
Finding living quarters	4	0	3	6	1	1	6	10
Obtaining higher/cont'g educ.	2	2	1	7	0	3	1	13
Recreation	2	0	4	7	1	1	5	11
Transportation	2	1	4	6	1	4	2	11
Developing self-care skills	2	3	5	3	0	7	6	5
Communication	2	0	2	9	0	2	3	13

*No = none; Mi = mild; Md = moderate; Sv = severe

Interagency Contacts. Administrators report on the frequency with which they contact five types of agencies: Vocational Rehabilitation, Developmental Disabilities, Public Health, Community Mental Health, and Blind Agency. (The latter was written in by a large portion of the respondents.) Their responses are shown in Table 6.9.

Table 6.9
Frequency of Contacts between Various Facilities and Respondents' School, by Age of Students

	12 Years and Under			13 Years and Over		
Type of Agency Frequency:*	Mnth	Year	Nvr	Mnth	Year	Nvr
Vocational Rehabilitation	2	5	5	4	7	9
Developmental Disabilities	2	6	4	5	6	7
Public Health	0	3	8	2	7	11
Community Mental Health	1	2	8	1	7	12
Blind Agency	4	0	8	1	2	17

*Mnth = monthly or more frequently; Year = several times a year or annually; Nvr = never contacted

Note a slightly larger portion of the schools for older students report no contact with VR (9 of 20) than do schools for younger students (5 of 12). VR and DD agencies are most frequently in contact with the schools. Public Health and Community Mental Health agencies have contact with about one third of the schools, with no particular difference between the two age groups. Surprisingly few of the schools for older students have any contact with their state agency for the blind (only 3 of 20), while almost twice the proportion of the schools for younger students do report contact with that agency (4 of 12).

Only a small number of the Administrators have rated the helpfulness of their contacts with the various agencies. Those who had little or no contact with a particular agency lacked a basis for judging that agency, although we could have entered a score of poor, properly representing the agency's uselessness to that school. On the other hand, such a manuever suggests more information than is available in this item. We pursue a conservative course. Assigning 4 points for a rating of excellent, 3 for good, 2 for fair, and 1 for poor, we have calculated an average for each of the agencies. VR rates 2.1 with Administrators of schools for younger students and 1.9 with those for older students. DD rates 1.8 with the younger and 2.1 with the older. PH rates 1.7 with the younger and 2.0 with the older. Community MH rates 1.9 with the younger and 1.7 with the older. The four schools rating the Blind agencies, two older and two younger, all assigned a rating of excellent.

Parent Involvement: Administrators' Views. Only 4 of the schools serving younger students and 8 of those serving older children report having a formal parents' group. The purposes of these 12 groups are to serve as advocates (6), to improve services (3), and to plan and fund activities (3). All of the parents belong to 1 group, more than half to another group, about half in 2 groups, and less than half in the remaining 8 groups. Meetings are held annually by 2 groups, several times per year by 6 groups, and monthly by 4 groups. The Administrators regard 5 of the groups as very effective, 6 as moderately effective, and 1 as ineffective. When judging parent involvement, Administrators of programs for younger students find parents more interested than do Administrators of programs for older students. The results are summarized in Table 6.10.

Table 6.10
Administrators' Ratings of Parent Involvement, by Age of Students

Ratings	12 Years and Under	13 Years and Over
Most parents are interested and participate	9	2
Most parents are interested but do not participate	4	11
Most parents have little interest and involvement	1	7

The Administrators report that they provide all parents with (a) periodic formal reports, (b) opportunities to participate in the IEP process, and (c) opportunities to visit their child's program. All but one give parents updated IEP information, and all but two offer parents an opportunity to participate in special activities. Ten of the 14 programs for younger students and 14 of the 20 programs for older students give parents an opportunity to participate in setting policies and procedures. With regard to evaluation, 7 of the younger programs do give parents an opportunity to participate, while 17 of the older programs similarly do so---a significant difference on this one point.

Placement Options. Administrators feel the need for additional placement options for their students. Twenty-two of 32 state that they have had students rejected by other facilities. The reasons given for not accepting the referrals are: too low functioning (8), no funds (8), no room (7), and behavior problems too severe (5). Seven Administrators of programs for younger students say that placements options are sufficient and 7 that they are not, while 8 Administrators of programs for older students feel placement options are sufficient and 12 that they are not. Two Administrators say there are no other placement options in their area. Table 6.11 shows the placement options now available to the Administrators, with their assessment of the appropriateness of each. The Administrators say the most urgent need for additional placement options are: community-based group homes (8), sheltered workshops (5), adult job training facilities (5), activity centers (5), community-based facilities, unspecified (3), custodial care (3), evaluation centers (2), prevocational training program (1), and adult center, unspecified (1).

Table 6.11
Placement Options Available to Administrators, by Rated Appropriateness and Age of Students

	12 Years and Under		13 Years and Over	
Option	Appropriate	Inapp.	Appropriate	Inapp.
Local education agency	6	0	8	0
MH/MR facility	2	0	2	3
HKNC	0	0	0	1
Sheltered workshop	0	0	2	1
Group living	1	1	2	0
Home	1	3	2	3
School for deaf students	2	1	1	2
State institution	2	1	0	0
Residential school, unspecified	1	0	0	0
Other	0	0	3	0

Opinions of Major Problems/Successes: Administrators. The major problems the Administrators see are poor communication (8), inadequate funding (6), inadequacy of facilities for postschool placement (5), lack of trained personnel (5), need for lifelong services (4), and the wide range of students' functioning levels (2). Asked for suggestions to solve these problems, Administrators most often urge more funding (16) or continue VI-C funds (9). Other suggestions are: remove upper-age limits (3), restructure service delivery (3), and provide more trained personnel (2).

Eleven Administrators regard the greatest success in the education of deaf-blind children as the increased independence gained (11). Increased public awareness (6), more specially trained personnel (6), serving previously denied children (3), and better training for students (3) are the other major successes from the Administrators' points of view. Also mentioned are funding (2), networking (1), better identification (1), and early training (1).

Teachers

The Teachers have been drawn from the schools managed by the Administrators whose responses have been analyzed above. The Teachers' characteristics are first displayed and then those of the segment of students for whom they are responsible, a subsample that, of course, differs somewhat from that represented by the Administrators. With that orientation to their background, analysis of the Teachers' responses proceeds.

Description of the Teachers. Table 6.12 shows the educational qualifications of the Teachers by the ages of students they teach. The Teachers of younger children tend to be somewhat better educated than those of older children, though the difference is not statistically significant and the former Teachers have proportionally more specialized training for their positions than do those teaching older students.

Table 6.12
Educational Degrees of Teachers and Special Preparation for Work with Deaf-Blind Students, by Ages of Students

Degree/Special Training	12 Years and Under	13 Years and Over
High School only	0	1
Bachelor's	6	8
Master's	7	9
Special Preparation to Teach Deaf-Blind Students		
Yes	6	5
No	7	13

All of the Teachers of younger students have had some inservice training, while 14 of the 18 Teachers of the older students have also had such training. Teachers of younger students average 5.5 years teaching disabled children and 3.9 years teaching deaf-blind students. Teachers of older students average 6.0 years teaching disabled students and 4.0 years teaching deaf-blind students.

Description of the Student Sample: Teachers. The students tend to have disabilities in addition to their deafness and blindness, as noted in the description of the entire sample above (see Table 6.1). The total number of students in the younger group (12 years of age and under) is 78; in the older group (13 years of age and older) it is 114. The sex distribution is interesting: the younger group consists of 43 males and 35 females, while the older group has 70 males and 44 females.

Educational Setting. The Teachers describe their educational settings as residential (12), other (7), day school (5), custodial institution (5), special class in regular school (2), and itinerant (2). (One Teacher each in the younger and older group characterized the setting by checking two categories.) The settings appear well represented by the sample.

Student Evaluations. Table 6.13 contains an analysis of the Teachers' responses to the request for information about student evaluations of various kinds. Among younger students, audiological examinations are most frequently given, followed by evaluations of self-help skills and general behavior. To the extent that elapsed time since last evaluation indicates frequency, the general physical examination is most often given, though to a relatively restricted group of the younger students. Speech and language and vocational evaluations (the latter to only 7 students) are also very recent. For the older students, visual and auditory examinations are given to the most students. General physical examinations and intelligence tests are also very frequently done. Most current is the vocational evaluation, with assessment of self-help skills, general behavior, and prevocational skills next most recent.

Table 6.13
Number of Students Evaluated, by Type of Evaluation, Average Time Since Last Evaluation, and Students' Ages

	12 Years and Under		13 Year and Over	
Type of Evaluation	N	Avg Time (Mos)	N	Avg Time (Mos)
Visual Examination	60	11.1	86	9.3
Auditory Examination	82	10.5	86	8.7
Intelligence Test	61	14.2	80	10.6
General Physical	53	4.8	83	7.8
Academic Achievement	63	7.2	79	8.5
Speech and Language	55	5.1	62	8.1
Mobility	72	8.8	52	8.0
Self-Help Skills	73	7.2	71	6.1
General Behavior	73	7.2	65	6.5
Prevocational	29	11.5	41	6.8
Vocational	7	5.6	29	4.9

Asked if they regard the various examinations as satisfactory, Teachers are almost universally accepting of them. Of the 31 Teachers, only 5 are dissatisfied with intelligence evaluations, 3 each with visual and general-physical examinations, 2 each with auditory and prevocational assessments, and 1 each with speech-and-language and vocational evaluations. The Teachers unanimously are satisfied with academic, mobility, and self-help-skills testing.

Appropriateness of Placement. Teachers generally believe that students assigned to them are in the proper educational setting. Only 14 younger and 13 older students are considered misplaced. The reasons given for inappropriateness of placement generally involve the students' low functioning, so low that little can be accomplished in the present classroom.

Curriculum and Instructional Materials. Twelve of the Teachers of younger students and 13 of the Teachers of older students make use of a formal curriculum. However, no one of the 12 curriculums named is used by more than one, except for the Koontz Brignance Diagnostic Inventory of Early Development which is used by 2 Teachers. Only 2 of the 5 Teachers of younger children express satisfaction with whatever curriculum they are using, as do 5 of 8 of the Teachers of the older students. The principal reasons given for dissatisfaction are the lack of specificity for deaf-blind students (5) and insufficiency of teaching options (2). No specific recommendations have been given as to how the situation might be remedied, except to suggest that more funds be made available and that, indeed, something be done.

The majority of the Teachers are satisfied with present instructional materials: 8 of the 13 Teachers of younger students and 11 of the 18 Teachers of the older students. Of the 12 who are dissatisfied, 7 feel that they do not have better materials from which to choose, while 8 do not have adequate funds. Among the suggestions for improving instructional materials, the requests for more tactually stimulating materials (4) and for more materials involving gross-motor movements (3) predominate. With regard to instructional equipment, the Teachers of the younger students, with one exception, express satisfaction with what they have. Six of 17 Teachers of older children, however, are not satisfied with the equipment they have. Five do not know of better equipment, though they would like to have it, and 3 lack adequate funds to buy equipment they need.

Physical Plant. Most of the Teachers have no complaints about their present quarters. Nine Teachers of younger students and 14 Teachers of older students say they are satisfied with their present location. Of those who are not satisfied, the principal complaint is that they do not have sufficient space (7). Three believe their building needs repairs, and 5 that it lacks essential features. With regard to the latter, 4 mention that their quarters are cramped, 2 that shelves are needed, and 2 that the rooms do not have carpets. The remaining points are made by only one Teacher each.

Communication. Teachers use a broad array of techniques with which to communicate with their students. The methods now being employed are summarized in Table 6.14. They are arranged to reveal any differences between what Teachers tend to use with younger and older students. With the exception of visual sign, however, such differences in communication do not emerge from these data. The most frequently used methods, irrespective of the age group, are sign language, either visual (21) or hand-on-hand (16). Speech is the next most common method, being used without amplification by 12, with group amplification by 2, and with individual amplification by 18. Fingerspelling, regardless of the alphabet, is used by only 11 Teachers. Tactual print in the form of Braille (4), Lorm (2), or Moon (2) codes are also little used by the Teachers in this sample, as are Tadoma (3) and communication boards (6).

Table 6.14
Methods of Communication Used by Teacher Respondents, by Ages of Students

Method	12 Years and Under	13 Years and Over
Unamplified Speech	5	7
Group Amplification	1	1
Individual Amplification	8	10
Tadoma	1	2
American One-Handed Alphabet	4	2
American Two-Handed Alphabet	1	2
British Two-Handed Alphabet	1	1
Sign Language, Visual	7	14
Sign Language, Hand-on-Hand	6	10
Braille	2	2
Lorm Alphabet	1	1
Moon Alphabet	1	1
Communication Board	2	4
Other	2	0

Support Staff. Most of the Teachers have aides: 11 Teachers of younger students, with 2 having two aides, and 14 Teachers of older students, with 6 having two aides. All of those who have aides are satisfied, 17 of 23 completely and 6 of 23 most of the time.

Table 6.15
Number of Support Staff and Rating of Quality

Type	Total	Excellent	Good	Fair	Poor
Physical Therapist	21	9	6	3	3
Movement Therapist	1	1	0	0	0
Speech Pathologist	25	11	9	3	2
Parent Counselor	7	3	4	0	0
Occupational Therapist	18	13	2	1	2
Guidance Counselor	4	3	1	0	0
Interpreter	4	2	2	0	0
Reader	2	2	0	0	0
Physical Education Teacher	16	9	4	3	0
Prevocational/Vocational Teacher	14	6	7	1	0
Mobility Instructor	13	7	6	0	0
Social Worker	22	6	11	4	1
Psychologist	24	6	7	8	3
Rehabilitation Counselor	3	0	3	0	0

Table 6.15 summarizes the information with respect to other support staff. The most frequent professions represented in the schools are speech pathologists (25), psychologists (24), social workers (22), and physical therapists (21). The least are notetakers (0), movement therapists (1), readers (2), rehabilitation counselors (3), guidance counselors (4), and interpreters (4). In general, the support staff is well-regarded by the Teachers. However, the psychologists rate between fair and good (17 on a scale from 1 to 30); the social workers, physical therapists, and rehabilitation counselors have the next lowest scores, 20, indicating an average rating of good. The remaining staff all have average ratings between good and excellent.

Parent Involvement. Of the 29 Teachers responding to the question about their contacts with parents, only 4 say they have had no contacts with the parents. The remainder have been in touch with the parents at meetings (13), on the telephone (8), through visits from parents (2), by home visits (1), and by letter (1). Twenty-four of the 26 Teachers rate the quality of the contacts as satisfactory, but only 20 of 27 Teachers rated the frequency of contacts satisfactory. They have almost no suggestions as to how to improve frequency; one suggests that the social worker should be given responsibility and another that a conference be called.

Student Involvement. The Teachers have responded that 24 of the deaf-blind students are able to participate in the development of their IEPs. The question, however, asks if the students can participate "to some extent." It does not distinguish between minimal and full, or substantial, participation.

Teachers' Assessments of Students. Teachers predict very low-level accomplishments for their students. Teachers do not believe that the majority of their students can live independently; even a group home appears difficult; 68 students are believed suited only for custodial care. Only 12 are thought to be eventually capable of competitive employment, and only 66 of sheltered workshop placement. Sixty-six are believed to be incapable of any employment. Teachers forecast that only 38 will benefit from secondary education and only 17 from postsecondary education. The results of the inquiry are shown in Table 6.16.

Table 6.16
Teachers' Predictions about Students, by Age of Students

Prediction	12 Years and Under	13 Years and Over
Able to live independently	5	5
Able to live in group home	30	68
Will need institutionalization	31	37
Capable of competitive employment	2	10
Capable of sheltered work	23	43
Incapable of any employment	25	41
Will profit from secondary educ.	12	26
Will not profit from secondary	31	51
Will profit from postsecondary	10	7

Job Satisfaction. Teachers' attitudes toward various aspects of their present positions are shown in Table 6.17. They are highly satisfied with their supervision. They are only a little less satisfied with their working conditions, their salaries, and their inservice training. They are relatively dissatisfied by their students' progress and by their own educational preparation. When asked if they plan to return to their present position next fall, the 27 of the 30 Teachers respond yes, a response rate consistent with their other replies. Of the 3 not planning to return, 1 expects to retire, 1 return to school, and the other will continue in the education of deaf-blind students.

Table 6.17
Teachers' Ratings of Aspects of their Positions

	Satisfied		Dissatisfied	
Aspect of Employment	Very	Moderately	Moderately	Very
Supervision	17	7	4	2
Working Conditions	14	8	5	3
Salary	12	11	5	2
Students' Progress	7	15	3	4
Own Educational Preparation	6	15	7	2
Inservice Training	12	14	3	1

Opinions of Major Problems/Successes: Teachers. The most frequently cited problem by Teachers in the education of deaf-blind students is the poor quality of staff (10). This finding is presaged by the Teachers' own relatively low opinion of their own educational preparation (see Table 6.17). Slow progress of their students (4), lack of funds (3), and limited program options (4) are the next most common vexations. Mentioned by only one Teacher are: too many students, lack of continuity in teaching self-care, and poor student motivation.

Asked for suggested solutions to the problems they posed, the Teachers respond better training (14) and more money (3). Three other suggestions are: group homes, restrict students' medications, and a very pessimistic "nothing."

The principal success in the education of deaf-blind children, as judged by the Teachers, is the provision of better services (15). Deinstitutionalization or preventing institutionalization was mentioned by 4 Teachers. Two specified better communication. One pointed to increased parental involvement. The remaining third of the Teachers did not respond to this item.

Parents

Returns have been received from 44 Parents. Their replies indicate that they are well-educated: both husbands and wives have completed an average (median) of 12.1 years of education. The wives' educational range is from 5 years to 17+ and the husbands' from 3 to 17+. They are generally free of disabling conditions: 38 of 40 wives and 32 of 36 husbands do not have a physical or sensory disability. However, 5 families have more than one child with a visual or hearing disability.

Regarding their deaf-blind child, the median Parents first suspected the hearing impairment at 10 months of age; on the average, diagnosis of the condition was made at 14 months. The visual impairment was suspected at 7 month of age and the diagnosis made between 9 and 10 months of age. Educational services were obtained for the average child at 41 months of age.

Of the 41 children for whom the Parents provided information, 30 are now in residential schools and 11 in day schools. The average child has been in the present educational placement for 7 years.

Educational Progress. The Parents generally regard their children's educational progress as between fair and poor. Their ratings of specific educational aspects are shown in Table 6.18. The most highly regarded area is that of daily living skills; the basic academic areas, reading, writing, and mathematics, are rated the lowest. The large number of Parents who checked Doesn't Apply for these three categories is revealing in itself: Reading, 25; Writing, 26; Mathematics, 25. Given the fact that the deaf-blind children whose educational progresses are being rated have been in school for an average of 7 years, these ratings indicate that the Parents' expectations for more than half of them are quite low.

Table 6.18
Parents' Ratings of Children's Educational Progress

Area	Median[1]	Excellent	Good	Fair	Poor
Skills of Daily Living	2.8	13	10	11	5
Communication	1.9	0	10	17	12
Reading	0.3	0	4	4	8
Writing	0.3	0	3	4	8
Mathematics	0.3	0	3	4	9
Mobility	2.6	3	20	7	7
Recreation	2.1	3	13	10	7
Independent Living	1.1	1	4	12	8
Social Behavior	2.0	4	11	12	8
Vocational Preparation	1.4	3	7	10	7

[1] Based on Excellent = 4, Good = 3, Fair = 2, Poor = 1, and Does Not Apply or Nonresponse = 0.

Educational Placement. Despite their modest ratings for their children's educational progress, most Parents say that their children are in the proper educational setting. Only 4 of 41 would like to move their children: 2 to a better-funded, better-staffed program, and 1 each to either a private program or one that offers "behavioral management."

Communication in the Home. Of the 34 Parents who responded to the query about communication in the home, 24 say they sign to their deaf-blind children (17 sign and 7 use "home signs"), 9 speak, and 1 uses "touch." Asked if communication with their deaf-blind child is satisfactory, 30 answer yes and 11 no.

Agency Contacts. Table 6.19 displays the responses of the Parents to the request that they indicate what agencies in their states they have contacted and for a rating of the quality of service they received. The most frequently contacted agency is Social Security, which receives a rating almost at good. Parents indicate very little contact with the remaining agencies, and they rate what contacts they have had a little above poor.

Table 6.19
Number of Parents Contacting Various State Agencies, by Quality of Service Received

Agency	Median*	Excellent	Good	Fair	Poor
Vocational Rehabilitation	0.2	3	6	1	1
Social Security	1.9	4	10	9	4
Mental Health	0.2	2	6	2	2
Speech & Hearing Center	0.3	5	6	3	0
Public Health Agency	0.2	1	8	0	1
United Fund Agency	0.2	2	6	2	1

*Based on Excellent = 3, Good = 2, Fair = 1, Poor = 0.

The lack of agency contacts does not appear based on the Parents' lack of need for support of various kinds. As shown in Table 6.20,

Table 6.20
Parents' Ratings of Needs for Various Services

Service	Median*	Very Great	Moderate	Mild	None
Financial Aid	1.3	8	11	9	13
Information about Deaf-Blind	2.0	14	12	5	10
Information about Services	2.3	18	12	4	7
Medical Care for Child	1.8	16	6	10	9
Vocational Preparation	1.8	13	11	7	10
Communication Training	2.4	19	10	5	7
Equipment to Improve Communication	1.4	11	8	7	14
Legal Advice/Services	1.4	14	5	10	12
Respite Care	0.6	11	3	6	19
O.T. or P.T. for Child	1.6	11	10	6	14
Speech-Language Therapy	1.7	12	11	3	15
Daycare or Babysitting	0.5	7	5	6	20
Counseling	0.5	12	2	6	21

*Based on Very Great = 3, Moderate = 2, Mild = 1, None = 0.

Parents feel that, next to Communication Training, obtaining Information about Services is the greatest problem of those listed. Third highest on the list is Information about Deaf-Blindness, a rather surprising response, when one considers that this sample's children have an average of 7 years in school, so the Parents have had a deaf-blind child in their families for an average of 11 years. Parents express little need for counseling, respite care, or day care. Their greatest problem, as expressed here, is obtaining Communication Training.

Organizations Joined. Asked about organizations they have joined since learning they have a deaf-blind child, Parents show a small inclination to seek organizational support. Only 22 of the 44 Parents say they have become members of a group in order to receive help in connection with their children. Some, however, have become members of several organizations: Mental Health/Mental Retardation, 11; National Association for the Deaf-Blind, 5; Parent-Teacher Association, 4; and 1 each of unspecified organizations.

Parent Participation. The Parents in this sample indicate that they have a fair degree of involvement in their children's education. As shown in Table 6.21, most receive formal progress reports from their children's schools, and many say that they visit the programs and participate in the planning for their children's education. Less than half evaluate the educational programs or participate in establishing policies and procedures in the schools.

Table 6.21
Number of Parents Participating in Children's Education, by Activity

Activity	...........Participation...........			
	Total	Yes	No	Nonresponse
Receive Formal Reports	44	40	1	3
Participate in IEP	44	34	7	3
Receive Updated IEP Information	44	35	6	3
Visit Program	44	35	5	4
Participate in Establishing Policies and Procedures	44	18	22	4
Participate in Special School Activities	44	29	11	4
Evaluate the Educational Program	44	20	18	6

Current Problems. Parents have been given the list of problems shown in Table 6.22. They have been asked to indicate for each problem the degree to which they presently have the various difficulties. The results indicate that, consistent with the data in Table 6.19, the most pressing difficulty, as viewed by the Parents, is Communicating with the Child. The second most urgent problem is Finding Recreational Outlets for their children. Arranging for Corrective Surgery is at the bottom of the list, a little below Obtaining Respite Care. Of course, these responses reflect the problems faced by Parents who have schoolage children. As will be seen, the Parents take a different view of the futures for their deaf-blind children.

Table 6.22
Parents' Ratings of Problems They Now Encounter

Type of Problem	Median*	Severe	Moderate	Mild	None
Transportation	0.3	3	7	4	27
Respite Care So Parents Can Go On a Vacation	0.2	5	2	6	28
Earning Sufficient Money to Pay for Child's Care	0.6	5	7	9	20
Developing Child's Self-Care Skills	1.1	8	7	12	13
Finding Recreational Outlets for the Child	1.8	12	12	1	16
Arranging for Future Guardian	0.9	13	4	6	18
Appropriate Education Service	0.4	7	5	5	24
Obtaining Appropriate Educational Psychological Evaluation	0.4	4	6	8	22
Communicating with Child	1.8	12	11	8	9
Architectural Accessibility	0.3	3	5	5	26
Getting Medical Services	0.5	5	5	10	20
Corrective Surgery	0.1	1	3	5	31
Obtaining Equipment (e.g., Hearing Aids, Wheelchairs)	0.3	3	4	8	25

*Based on Severe = 3, Moderate = 2, Mild = 1, None = 0.

Estimates of Future Problems. The Parents have, on the average, a very dim view of their children's futures. As seen in the next table, most believe their child will live in a group home, doing either sheltered work or none, having had no benefit from secondary education.

Table 6.23
Number of Parents Choosing Each of Following Predictions about Their Children's Independence, Employment, and Education

Prediction	Number
Living Arrangement	
Will be able to live independently	1
Will be able to live in a group home	25
Will need institutionalization	9
Nonresponse	9
Employment	
Will be capable of competitive employment	2
Will be capable of sheltered employment	19
Will be incapable of any employment	17
Nonresponse	6
Education	
Will profit from postsecondary education	7
Will profit from secondary education	4
Will not profit from secondary education	21
Nonresponse	12

Asked about the major problems confronting the education of deaf-blind children, the Parents reply not enough program options (11) or money (10), lack of knowledge (3) and trained staff (2), and problems of communication (2).

Their solutions for these problems are straightforward: more money (11), more options (5), more staff (4), and an improved deaf-blind curriculum (3).

Asked to specify the major successes in the education of deaf-blind children, the Parents provide the following list:

Good Staff (10),
IEP (4),
More Programs (3),
Integration (1),
Group Homes (1).

Deaf-Blind Adults

The 50 deaf-blind Adults range in age from 21 to 55 years, with an average 35.9 years of age. The 19 females have a mean age of 36.6 (median = 33.0), and the 31 males have a mean age of 35.5 years (median = 34.1). They lost vision and hearing early in life, becoming auditorily impaired at a median age of 4 months (mean = 4.5 years) and visually impaired at a median age of 7.5 years (mean = 12.1 years). Twenty-nine were born deaf, and 16 born blind. In addition to being deaf-blind, 9 report that they have additional disabilities: 3 heart disorders, 2 orthopedic, and 1 each arthritis, cerebral palsy, diabetes, seizures, ulcers, vestibular problems.

Education. The Adults' education began, on the average, at 5.2 years of age. Four respondents had itinerant teachers come to their homes before they started school, two when they were 1 year old. The Adults' median years of education is 14. The range is from 5 years to 17+ years. Fourteen have attended college; 7 earned bachelor's degrees and 3 master's degrees. Asked to rate their education, the Adults consider it to be a little less than good (see Table 6.24). On the plus side, they see their education as having provided communication (8), mathematics (5), stimulation (4), good teachers (4), history (1), support services (1), and trade courses (1); but 14 reply that there was nothing good about it. On the negative side, 4 named the oral method, 4 poor teachers, 3 lack of communication, and 3 limited and boring programs. Nineteen said they could cite no bad aspects of their education.

Table 6.24
Deaf-Blind Adults' Ratings of Own Education

Rating	Number
Excellent	7
Good	20
Fair	16
Poor	6
Nonresponse	1

Agency Contacts. Forty of the 50 Adults have been in contact with their states' VR agencies. As shown in Table 6.25, those who rate their first contacts do so quite favorably, giving the agencies ratings somewhat better than good, on the average. Also in Table 6.25 are ratings by the 25 Adults have had contact with their state agency for the blind. Though a fraction lower, the ratings for the blind agencies are almost the same as for the VR agencies.

Table 6.25
Deaf-Blind Adults' Ratings of Quality of Service Received at
First Contacts with their State VR and Blind Agencies

State Agency	Number	Median*	Excellent	Good	Fair	Poor	DNR**
VR	40	2.2	8	15	6	8	3
Blind	25	2.1	8	7	7	2	1

*Based on Excellent = 3, Good = 2, Fair = 1, Poor = 0.
**Did not rate

Employment. The employment status of the Adults is shown in Table 6.26. The majority are in the labor force, with 5 of the 31 presently unemployed. Of those not working, 3 last worked in 1982, 15 last worked between 1977 and 1981, 3 before 1977, and 3 never worked.

Table 6.26
Distribution of Deaf-Blind Adults by Labor-Force Status and Employment:
1982

Labor Force Status	Number
In Labor Force	31
Employed	26
Unemployed	5
Not in Labor Force	17
Status Undetermined	2

Occupational Background. The Adults have held or are now holding a wide range of occupations. These range from positions in the technical-professional category, the highest, to laborer, the lowest in the Bureau of the Census classification of occupations. The distribution of positions presently or last held is shown in Table 6.27. Attention is directed to the 11 Adults in the highest occupational category: 4 teachers, 3 managers, and 1 each rehabilitation counselor, librarian, community relations consultant, and accountant. These individuals demonstrate the wisdom of not placing upper limits on the employment potential of any individual, regardless of nature and extent of their disabilities. It should be cautioned, however, that the table cannot be directly interpreted, since some of the Adults do not have the positions shown. These may have been lost as a result of their deafness or blindness; that is the case for some of those whose second sensory disability was acquired after employment had been gained.

Table 6.27
Distributions of Present or Last Occupation Held by Deaf-Blind Adults

Occupation	Number
Assembler (typewriter, telephone, etc.)	7
Machine Operator	7
Packer, Shipper, Mail Clerk	5
Teacher	4
Service Worker	4
Food Service Manager	3
Automotive Mechanic	2
Broommaker	2
Janitor	2
Nurse's Aide	2
Teacher's Aide	2
Rehabilitation Counselor	1
Accountant	1
Community Relations Consultant	1
School Librarian	1
Shoemaker	1
Medical Records Clerk	1
Hospital Attendant (Operating Room)	1
Never Worked	3

Other considerations aside, however, the list of occupations in Table 6.27 indicates that the Adult sample is relatively high level in terms of demonstrated occupational potential. The majority of the Adults stated that they obtained the positions shown simply by applying for them (23) or having them offerred to them (17). They secured the positions by themselves in 16 instances and with help in 30. The most frequently named helper, by those who provide that information, is VR (19), followed by their schools (6), friends or family members (5), private employment agency (1), and state unemployment office (1). On the whole, those who are (or were) employed are satisfied with their last position: very much (17), moderately (18), a little (5), not at all (7). Those who are a little or not at all satisfied give as reasons for their dissatisfaction: pace too fast (7), boring or unchallenging (4), and too confusing (2). Of those who have worked or are now working, 43 say their employers have made no accommodations for them. For the other 4, employers provided additional light for 2, and for 1 each, a mobile cabinet, a TTY, and an interpreter.

Income. Earnings of those who are presently employed are fairly low. The mean income is $6,903, from wages and salaries; and the median is $6,251. Compared to Bureau of the Census estimates for 1979, which should give some advantage to the Adult comparison, the discrepancy is substantial: employed females in that year had a median income of $10,550, and males, $17,514 from wages and salaries.

Most of the Adults (37 of 50) have other sources of income than their own salaries and wages. SSI accounts for 34 of them, 2 receive funds from parents, and 1 has an annuity that has matured. Nonetheless, as a group, the Adults can hardly be considered affluent.

Living Arrangements. Thirteen of the Adults live alone; 18 live with one other person, 8 live with two other persons, 10 live with three other persons, and 1 lives with four other persons. Fourteen of the Adults live with their spouse. The spouse is also deaf-blind in 3 instances, hearing-impaired in 8, and unimpaired in 4. Only 17 have ever been married. Fifteen remain married, 2 are divorced, and 1 is widowed.

The present living quarters occupied by the Adults are well-rated by them: very good, 23; good, 23; fair, 3; poor, 1. Of those who say that their quarters are fair or poor, their reasons are lack of necessary repairs (3), cold and damp (2), and bad neighborhood (1).

Communication. Table 6.28 shows the communication methods known by the Adults, along with their communication preferences. The best-known method is the American One-Handed Alphabet; fingerspelling in this code is the second most-preferred communication method. Sign language is the most-preferred means of communication, when used visually; in the hand-on-hand version, it ties with individual amplification for the third position in methods that can be used. Braille is the fourth-best known communication method, but none of the Adults express a preference for its use. The figures in Table 6.30 illustrate vividly the wide range of communication options available to deaf-blind persons and, equally vividly, the imperfect relationship between what the Adults know and what they prefer to use in communication.

Table 6.28
Adults' Knowledge of and Preferences for Communication Methods

Method	Know	Preferred
Speech, Unamplified	10	5
Group Amplification	3	1
Individual Amplification	17	7
Tadoma	4	0
American One-Handed Alphabet	41	9
American Two-Handed Alphabet	12	0
British Two-Handed Alphabet	5	1
Sign Language, Visual	31	20
Sign Language, Hand-on-Hand	25	7
Braille	20	0
Lorm	1	0
Moon	1	0
Communication Boards	3	0
Tellatouch	6	0

Communication and Mobility Aids. The Adults use, but do not necessarily own, the variety of aids shown in Table 6.29. Seven Adults do not use any aids. The most commonly used aid is the cane (26) and the next most used aid is the personal hearing aid (20), with the TDD (19) very close behind in terms of number who use it. The Wrist Com and the Versabraille are not mentioned by any of the Adults.

Table 6.29
Number of Adults Using Various Aids to Communication and Mobility

Aid	Number
Cane	26
Personal Hearing Aid	20
TDD	19
Tellatouch	8
Vibralert	6
Optacon	3
Telebraille	2
Wrist Com	0
Versabraille	0
None	7

Problems of Adults. Three approaches are used to elicit the Adults' views of conditions affecting their lives and the lives of other deaf-blind adults. The first requests their ratings of eight problems in terms of their own lives. The second asks them to rate their needs for a variety of services. The third elicits their views of the problems faced by deaf-blind adults in general. Responses to the three lists should complement each other. Table 6.30 displays the tabulation of responses to the first query.

Table 6.30
Adults' Ratings of a List of Problems That May Affect Them

Problem	Median*	Severe	Moderate	Mild	None
Earning a Living (Working)	1.8	23	6	9	11
Attendant Care	3.8	4	4	5	37
Living Quarters	3.7	9	2	8	31
Higher/Continuing Education	3.6	14	2	7	27
Recreation	2.8	16	7	8	19
Public Transportation	3.1	14	4	11	21
Self-Care Skills	3.7	4	4	10	32
Communication	2.4	17	9	9	15

*Based on Severe = 1, Moderate = 2, Mild = 3, None = 4

Despite their record of previous employment and their present rate of employment, the Adults give first priority amongst the problems to Finding Employment. It falls below severe, almost to moderate. The next problem in order of the ratings is Communication, rating about midway between moderate and mild. Recreation is third, falling below moderate almost to a rating of mild. The fourth problem is being able to use Public Transportation. It is rated a bit below mild.

The most desired service is for Vocational Preparation. Communication Training ranks second in the list of services needed by the Adults. Financial Aid is the third item in the list, followed closely by Use of Equipment to Improve Communication. See Table 6.31.

Table 6.31
Services Rated by Adults as to Their Need for Them

Service	Median*	Great	Moderate	Mild	None
Financial Aid	2.7	13	10	10	17
Information about Deaf-Blindness	3.1	12	6	12	20
Medical Care	3.6	8	5	10	27
Vocational Preparation	1.9	22	8	6	14
Communication Training	2.3	18	9	10	13
Use of Equipment to Improve Communication	2.8	13	9	12	16
Legal Advice/Service	3.6	7	7	8	28
Respite Care for Parents	3.9	2	1	2	45
Corrective Surgery	3.8	4	3	5	35
Equipment (hearing aids, wheelchairs, etc.)	3.6	11	3	8	28

*Based on Great = 1, Moderate = 2, Mild = 3, and None = 4.

Table 6.32 presents the Adults' replies to the open-ended question about problems facing deaf-blind people.

Table 6.32
Adults' Views of Problems Facing Deaf-Blind People

Problem	Number
Social Life and Recreation	20
Communication (including Telephone Use)	17
Transportation and Mobility	12
Employment	5
Education	3
Interpreters	3
Housing	1
Don't Know	7

The most frequently mentioned category is Social Life and Recreation. It placed third in the list shown in Table 6.30, having a fairly high rating of severity. Communication is second on the list, as it is in Tables 6.30 and 6.31. Transportation and Mobility are a fairly close third in order of problems. A distant fourth in the mentions given by the Adults is Employment. Of the remaining three items, Interpreters might have been added to Communication, thereby placing the latter in a tie for first on the list of problems. However, it seems that it is worth considering Interpreters as a separate category, because the correction of the problem lies outside of the deaf-blind person and it is not a matter, as yet, of equipment. In the list of services (Table 6.31), Communication Training is rated as a very great need; having interpreters available does not necessarily reduce the need for communication training. Indeed, improved communication ability may increase the need for interpreters, a paradox quickly dissipated by distinguishing between communication modes and language.

Chapter VII
Syncretization

In preparing this recapitulation of the project's findings, recourse has been made to the Conceptual Framework described in Chapter V. The Conceptual Framework is designed to articulate the various decision points that confront service providers over the deaf-blind person's lifespan. These critical periods, of course, cumulate for any given agency and create the need for policies transcending that one agency and calling for the mobilization of community resources and large-scale, even national, efforts to develop the potential latent within deaf-blind people and to defend their basic physical, emotional, and spiritual integrity.

The discussions bring together the data from sources within the project (e.g., the familiarization study and the four surveys) and from outside the project (as represented by the literature). To assist the reader in the process of syncretization, copious references are made to the data sources in the preceding chapters of this report. Literature citations are as punctate as possible, citing either the page or the recommendation number for each point. References to sources within the report indicate the tables or sections in which the data can be found. The numbers heading each of the major sections of this chapter correspond to those in the Conceptual Framework.

1.0 Orientation to the Deaf-Blind Population

1.1 (Legal and Philosophic Basis for Services). The legal and philosophic bases for services to deaf-blind persons seems most clearly embodied in federal legislation, specifically, the Rehabilitation Act of 1973 and Rehabilitation Act Amendments of 1978 and Title VI-C and The Education of All Handicapped Children Act.

The first federal funding of programs for deaf-blind students came in 1968, with a modest appropriation that established the Regional Programs for Deaf-Blind Children. In the ensuing 14 years, funding has grown to about $16 million per annum. More important than the sums of money appropriated are the associated benefits of the Congressional action: the federal government has directed attention to the plight of these children, has provided leadership in developing resources (teachers, curriculums, etc.), and has monitored the progress of the various States in their efforts to serve this educationally difficult group. At a minimum, national leadership is essential to coordinated planning that transcends State boundaries. In particular, the most involved federal agencies, Rehabilitation Services Administration and Special Education Programs, can greatly aid the longitudinal care of deaf-blind individuals by regulating the coordination of IEP and IWRP.

1.2 (Definition of the Target Population), 1.3 (Characteristics of the Population), and 1.4 (Size and Distribution of the Population) must be considered together. As discussed at length in Chapters III and IV, the diversity of definitions leads to difficulties in establishing rates for and in determining the relevant characteristics of the deaf-blind population. Note especiallly the following reports cited in Chapter IV:

AIR, pages 25 and 46; FORUM, 1; MSA, page 7; NA, 1.0; MID, A-2 and A-5.

The use of several definitions in simultaneous contrast is suggested here as a means to avoid arid controversy, while explicating the nature of this condition. It is clear, however, that some continuing sources of information are essential to sound planning and evaluation of programs to serve deaf-blind individuals. The suggestion that a register be maintained to serve these purposes is additionally supported by MSA, page 31; NA, 1.b; MID, B-10; and NOW R-2. Both AIR, page 45, and MID, A-5 and B-18, urge the dissemination of statistics on the deaf-blind population.

National prevalence rates (such as those shown in Tables 3.1, 3.2, and 3.3) will not adequately serve local planning purposes. Geographical variations in rates must also be understood (for which see the discussion following Table 3.3). The finding that one region has a much higher rate for one category of deaf-blindness than any other region not only has planning implications, but also epidemiological significance.

1.5 (Communication). Literature bearing on this severe problem is reviewed in Chapter III. In Chapter IV, every organization representative contacted in the Familiarization Study noted the communication difficulties encountered by deaf-blind people. For example, Table 4.3 lists 15 communication methods used by deaf-blind people, whereas Table 4.7 shows that only six of the 14 direct-service programs visited have staff members who are proficient in most of the methods used by deaf-blind clients. Only five programs believe that all of the communication needs of their students are being met (Table 4.8), and of 13 programs asked if further development is needed in this area, 12 responded yes. Every respondent group in the four surveys expressed grave concern about the communication problems of deaf-blind people (see Tables 6.8, 6.14, 6.18, 6.20, 6.22, 6.32, 6.33, and 6.34)

2.0 Early Diagnosis and Intervention

2.1 (Screening), 2.2 (Diagnosis), and 2.3 (Service Delivery). Interviews done for the Familiarization Study and various reports reviewed in Chapter IV point out the cost-effectiveness of early diagnosis and intervention. Screening and Diagnosis interrelate with 1.2 (Definition) and 3.1 (Casefinding and Referral). The lack of cohesion in the professionals' views of this condition are abundantly clear; yet without some cohesion, the professions cannot work together to achieve an early and effective advance on deaf-blindness. In ranking the importance of various services, the three State groups interviewed rated early identification, early intervention, diagnosis, and evaluation as essential (Table 4.10). Note also the high rate of additional handicapping conditions among the deaf-blind school population (Table 6.1).

A detailed knowledge of the size and characteristics of the deaf-blind population is essential at every age level for planning and evaluation purposes. The collection and analysis of these morbidity statistics are properly the function of the federal government, since only national data will suffice for these purposes. Furthermore, no

State government can afford the costs of such data gathering, nor does any single State have the prestige, which the federal government has, to gain acceptance for a functional definition of deaf-blindness that will replace the chaotic assortment now extant. Within this same context, the federal program should include a systematic attempt at casefinding at all age levels, in order to direct deaf-blind people into programming relevant for them.

3.0 The Education Process

3.1 (Casefinding and Referral). The State administrators consider information and referral key services (Table 4.10). The Administrators of the programs surveyed report that they are not presently serving an estimated 10 percent of eligible deaf-blind students, and a few believe they have students who would be better served in other programs (Chapter VI, "Educational Setting and Purview").

3.2 (Assessment and Placement). Administrators, Teachers, and Parents seem agreed that current practices in assessment and placement are adequate, though there is some dissatisfaction; e.g., see the Teachers' opinions of psychologists (Table 6.15). Also, dissatisfaction with assessment increases with the age of the students (Table 6.5).

3.3 (Physical Restoration and Prosthetics). These appear to have low priority among all groups consulted.

3.4 (Individualized Educational Plan). Since the IEP receives no derogatory comments, it does not seem to be in need of any remedial action. However, there is frequent mention in the literature and in the familiarization interviews of the desirability of coordinating an individual's IEP and IWRP, so as to come closer to the ideal of a "continuum of services" for deaf-blind people.

3.5 (Curriculum). Little use is made of formal curriculums, and 3 out of 5 Teachers express dissatisfaction with what they are using (Chapter VI, "Curriculum and Instructional Materials). What is more, few teachers are aware of curriculums designed for deaf-blind students (Chapter VI, "Curriculum and Instructional Materials").

The double disabilities of deafness and blindness drastically slow educational progress beyond what either disability would effect alone. The present upper age limit for educational support of 21 years does not seem adequate for the majority of deaf-blind individuals. Connecticut's Board of Education and Services for the Blind is already serving clients through the age of 24 years. Michigan has adopted a similar policy. The additional four years' education can be especially important for those deaf-blind individuals who have spent a substantial portion of their educational years in residential facilities where they frequently develop behavioral problems that interfere with their potential for vocational achievement and their possibilities for independent living. An additional period of vigorous education might improve their chances for greater life success, far beyond the additional educational expense for the four years. Similar recommendations have been made in the literature (MSA, page 41; NA, 2.16; and MID, C-6).

3.6 (Teaching Techniques). These are not directly mentioned in the surveys or in the other sources, though teacher quality does receive comment, mostly favorable.

3.7 (Media Development). While media development does not receive any encouragement from the data gathered from the four surveys, every program representative interviewed but one has mentioned the need to develop communication aids (see Table 4.9).

3.8 (Personnel). Staffing is a concern, particularly when it is noted that almost one third of Teachers of younger students and nearly one tenth of Teachers of older students do not presently have a bachelor's degree (Table 6.6). See also Administrators' opinions (Chapter VI, "Faculty" and "Supporting Staff), in which the need for inservice training appears.

3.9 (Facilities). Only a minority of Teachers and Administrators regard facilities as inadequate (Chapter VI, "Physical Plant and Staff," under Administrators, and "Physical Plant," under Teachers). However, many of the facilities representatives interviewed anticipate problems in the near future, if their populations increase or become more disabled (Table 4.5). They list as potential needs additional equipment and space necessary to rehabilitation programs. In Table 6.2, note that 25 or 33 programs would be considered highly restrictive environments (7 custodial institutions and 18 residential schools), a finding that merits consideration.

3.10 (Counseling). Counseling does not have a high priority among Parents. What counseling is presently available seems to satisfy the majority of Administrators and Teachers.

4.0 The Habilitation/Rehabilitation Process

The State VR agencies have had little experience in serving deaf-blind adults. These agencies are also concerned about rationing their reduced funds (reduced, that is, by inflation). The deaf-blind client often takes a disproportionate amount of time to process and often entails a low probability of successful closure. What is essential to more placements of deaf-blind clients are increased openings in sheltered workshops, intensive efforts to gain management interest, and research on ways to tailor employment to avoid or overcome the physical limitations of the deaf-blind client. Individual State resources will likely require bolstering through specific federal efforts, in order to achieve these objectives. The records of employment success by deaf-blind persons who have received proper education, training, and counseling and who have been afforded an opportunity should be widely known, so that these programs will gain the strong support they deserve.

4.1 (Casefinding and Referral). The remarks made under 2.1 are apropos here.

Ironically, schools for blind children seldom have adequate otological-audiological services and schools for deaf children seldom have adequate ophthalmological-optometric services. Yet any loss of audition has far more serious consequences for a blind child than for a normally seeing child, and any loss of vision has similarly far more serious consequences for a deaf child. Money alone does not seem to explain this peculiar state of affairs with respect to vision and hearing programs. Leadership is also implicated as a factor in determining how schools allocate their resources. For deaf and for blind adults, programs are needed that educate them as to the risks they face of becoming deaf-blind and the steps they should take to avoid those risks. The role of these programs in casefinding is manifest (see Section 1.0 above).

4.2 (Diagnosis and Evaluation). This aspect does not appear to be a problem, though the Advisory Committee expressed concern that (a) cases are misclassified because of RSA coding, which has no category for the joint disabilities, and (b) some cases are undetected because the regulation requiring that deaf clients have careful visual examinations and blind clients have thorough auditory examinations are sometimes ignored.

4.3 (Physical Restoration and Prosthetics). Adults do not rate this topic among the important items in their personal economies, though they do make substantial use of various aids. Apparently, these are being obtained without great difficulty by the sample interviewed (Tables 6.31, 6.32, and 6.33).

4.4 (Individual Written Rehabilitation Plan). Coordination of an individual's IEP and IWRP is discussed in 3.4 above. The notion is supported throughout the literature (specifically, AIR, 4; MID, A-10, A-11, and A-12).

4.5 (Adjustment Training). This does not surface as a specific need, as seen by the four samples interviewed nor in the Familiarization Study. However, attention must be called to the very low opinions Teachers and Parents have of deaf-blind children's chances of a successful adulthood (see Tables 6.16 and 6.23). The implication could easily be drawn that severe adjustment problems, though presently unrecognized, may be forthcoming.

4.6 (Vocational Training). Further education is mentioned as important by all of the survey respondents (see especially Tables 6.31 and 6.32). Communication training, frequently mentioned as a problem, is certainly an important part of any vocational training program. The literature also strongly urges additional programs of job training, job development, and job placement to supplement existing programs (AIR, 1; FORUM, 3.5; MSA, page 29; NA, 5.1b and 6.1d).

4.7 (Postsecondary Education). This appears to have little relevance for a large proportion of the deaf-blind children presently in school as viewed by their Teachers and Parents (see Section 4.5 above).

4.8 (Personnel). The need for additional and better-trained personnel to deal with the anticipated increase in deaf-blind rehabilitation clients has had little mention, either in the interviews or the literature. Whether or not present rehabilitation facilities are adequately prepared for a substantial influx of deaf-blind clients is open to conjecture. This study, however, does not find specific evidence to support a high priority for this area.

4.9 (Transportation). Here is a high-priority item for the Adults (see especially Table 6.34). The MSA study (page 33) also urges research on the transportation needs of deaf-blind persons.

4.10 (Individual and Family Counseling, Placement, and Follow-Up). As noted above, counseling does not receive specific mention as a great need in the surveys. However, the poor employment status of the Adults, especially their low or absent earnings, supports increased attention to placement and follow-up in the vocational rehabilitation process. Note, again, the doleful predictions of potential employability made by Parents and Teachers (Tables 6.16 and 6.23). If these are not to become self-fulfilling prophecies, substantial efforts will be required.

5.0 Alternative Living Arrangements

The present rate of development of independent-living programs is very slow. While federal legislation has authorized such programs since 1978, the essential appropriations have not been forthcoming. These facilities are critical to the well being of deaf-blind adults, as stated in the literature: FORUM, 5; MSA, page 32; NA, 6.2b and 6.2c; MID, B-9 and C-13; NOW, R-5; and RIGHTS, Art. 4.

5.1 (Independent Living), 5.2 (Semi-Independent Living), 5.3 (Moderate Support Living), 5.4 (Substantial Support Living), and 5.5 (Maximum Support Living). The Parent and Teacher data (Tables 6.16 and 6.23---substantiated, in part, by the Adult data (Tables 6.26, 6.32, 6.33, and 6.34)---direct attention to the limited potential at this time for the deaf-blind children to achieve independent living. The data seem to warn of an impending problem of great proportions.

6.0 Social and Recreational Services

One of the tragic consequences of being deaf-blind is social isolation. Without sight and hearing, the afflicted individual has great difficulty maintaining contact with society. Radio and television are powerless to alleviate the loneliness and boredom during hours when the deaf-blind person is alone.

6.1 (Social Interaction) and 6.2 (Special Recreation Programs). The needs for greater social interaction and recreation are given the highest priority by the Adults (see Table 6.34) and by reports in the literature that recommend special recreational programs (MSA, page 36; MID, B-9; and RIGHTS, Art. 8). Intimately associated with this problem is Communication, the Adults' second highest priority. As with many of the problems, these two are closely intertwined. The Parents' and the Teachers' predictions about their children's potentials for independent living also speak to the need for special attention to this area. The depressed expectations of significant persons in the deaf-blind person's milieu might be countered by periodic surveys to determine trends in needs and to chart the accomplishments of deaf-blind adults (NA, 1.2a).

6.3 (Sensitization of Professionals). A program to develop awareness of and sensitivity to the deaf-blind population would seem worthwhile. How can one relate the accomplishments of the Adult sample (e.g., Table 6.27) with the predictions made by the Teachers (Table 6.16)? The Teachers may be facing reality with unclouded vision. However, optimism can hardly be considered a fault when dealing with severely handicapped young children.

7.0 Elderly Care

As deaf people and blind people grow older, they become increasingly at risk of deaf-blindness. Regardless of definition, the majority of deaf-blind persons are 65 years of age or older (Chapter III, "Age"). Elderly persons require special attention to their nutrition, their housing, and their social lives.

7.1 (Housing). This is already mentioned as a problem by a minority of the Adults in a sample that included no persons over 55 years of age (Table 6.33). It will likely become a greater problem, particularly in view of the predictions made by Parents and Teachers (Tables 6.16 and 6.23).

7.2 (Income Maintenance). Income probably deserves a high priority, given the earnings data from the Adult sample (Chapter VI, "Income") and the predictions by the Parents and Teachers about their children's potential for employment (Tables 6.16 and 6.23).

7.3 (Social Interaction and Recreation). See Section 6.0 above.

7.4 (Nutrition). Nutrition has received no specific mention in the material uncovered by this study, though it will probably be a problem because of the Adults' low incomes (Chapter VI, "Income").

7.5 (Health Care). Little interest is evinced in health care, but the Adults' low incomes suggest that this service, along with others, may become a problem (Chapter VI, "Income" and Tables 6.33 and 6.34).

7.6 (Transportation). See Section 4.9 above.

7.7 (Interagency Cooperation). While mentioned under Elderly Care, interagency cooperation is a topic that concerns professionals in both Education and Rehabilitation (Sections 3.4 and 4.4 above).

8.0 Family Support Services

No parent is prepared for the shock of deaf-blindness. Once it has afflicted their children, parents need information about it, practical suggestions for managing their children, and counseling to overcome the emotional blows they suffer. Along with these psychological comforts, the parents need relief, from time to time, from the incredible burden imposed by their children's continuous needs for attention. Such respite care is essential to the well being of the deaf-blind children's primary care providers, for if those responsible for looking after the children are not healthy, then the children's health is threatened.

8.1 (Counseling and Social Work). Neither of these services receive much favorable mention by respondents in the four surveys.

8.2 (Parent Training). Instruction for parents does seem to warrant some attention, in view of Teachers' ratings of the Parents with whom they are in contact (Chapter VI, "Parent Involvement"). One report assigns a high priority to parent training (MID, B-8). Programming for parents in general strongly concerns several literature sources: AIR, page 26; FORUM, 3; NA, 4.16 and 7.1a; and MID, B-14.

8.3 (Alternative Living Arrangements) See Section 5.0 above.

8.4 (Financial Planning and Assistance). These are urgent needs, judging from the Adult data (Chapter VI, "Income" and Table 6.33).

8.5 (Transportation). See Section 4.9 above.

8.6 (Communication). This need surfaces in each of the four surveys, but most forcefully in the Adult section (see Tables 6.32, 6.33, and 6.34). See also the discussion in Section 1.5 above.

8.7 (Respite Care). Relief for parents does not directly receive mention as a problem. In fact, Parents seem to deny it is a problem. However, the children's handicaps in addition to deafness and blindness, as shown in Table 6.1, for instance, make it likely that many will become a burden on their parents, a burden not often sensed while the children are in school. Professionals must also realize that, to many parents, requesting respite care equates with rejection of their children. MID, B-8 recommends federal funding for respite care.

8.8 (Parent Organizations). Little interest in organizations is shown by the Parent sample (Chapter VI, "Organizations Joined).

9.0 Staff Recruitment, Preparation, and Ongoing Training

9.1 (Selection of Staff). Administrators express some concern about their present staffs, particularly with respect to morale and training (Chapter VI, "Faculty" and "Facilities and Supporting Staff"). Their concern does not appear to be one of selection, though the low educational qualifications of some of the teachers (Table 6.6) may be due to a limited labor force from which to draw. The Teacher sample yields few suggestions of any morale problems (Table 6.17); their greatest dissatisfaction is with their own educational preparation.

9.2 (Preservice Training). Professional preparation is an important issue. As shown in Table 6.17, a significant proportion of teachers express dissatisfaction with their educational background. Several reports cited in Chapter IV advocate federal funds for personnel training (AIR, 2, page 26; BC, 11; MSA, pages 30 and 39; NA, 4.1; MID, A-6, B-3, C-10, and C-11).

9.3 (Inservice Training). Consistent with the evidence in Sections 9.1 and 9.2 is a high priority for inservice training. Several references appear in the literature to special training, particularly for counselors (AIR, 1; FORUM, 3.5; MSA, page 29; NA, 5.1b and 6.1d).

9.4 (Supervision). This management responsibility does not appear to be a problem from the Teachers' and Administrators' standpoints (Table 6.17).

9.5 (Retention of Staff). While retention of staff is not a severe problem, 18 Administrators do indicate their concern about employee turnover (Chapter VI, "Supporting Staff").

9.6 (Professional Interaction). Among the four samples interviewed and from the information gained in the Familiarization Study, this does not appear to be an issue of consequence at this time.

10.0 Research and Development

Concerted research-and-development efforts have not as yet been directed at this severe combination of disabilities. Much might conceivably be done to alleviate the suffering that they cause. Such efforts should not overlook programs that have been tried in foreign countries, especially the Scandinavian countries. Sweden, in particular, has undertaken some innovative approaches to putting deaf-blind persons to work. The two most critical areas, aside from employment are: communication and transportation. These latter two problems have been uniformly mentioned by the deaf-blind adults interviewed in this study (Table 6.33 and 6.34). Federal funding of research is advocated by AIR, 2, page 28 and RIGHTS, Art 7.

10.1 (Prevention). Prevention does not surface as an issue in the interviews, but the literature and good sense point to the value of a preventive, rather than remedial, approach to deaf-blindness. Three of the reports discussed in Chapter IV recommend the establishment of hearing and vision conservation programs (BC, 5; MID, B-4; and RIGHTS, Art. 4). See also the discussion in Chapter III, "Size and Characteristics of the Deaf-Blind Population," and Section 10.5 which follows.

10.2 (Prosthetics). See Section 4.3 above.

10.3 (Epidemiology). See Section 10.1 above.

10.4 (Teaching Techniques). See Section 3.6 above.

10.5 (Curriculum). See Section 3.5 above. In addition, the development of curriculum specifically for the care of residual auditory and visual abilities is urged by BC, B.3.

10.6 (Instructional Materials). Only a minority of Administrators and Teachers express a desire for more and/or improved instructional materials (Chapter VI, "Curriculum and Instructional Materials" in the Administrator's and Teacher's data reports).

10.7 (Assessment Instruments). For the most part, Administrators and Teachers are satisfied with the current status, though they are not particularly pleased by intellectual assessment (Tables 6.4, 6.5, and 6.13).

10.8 (Service Delivery). The Parents are unhappy about their ability to make contacts with appropriate programs, as are the Adults (see Table 6.33, noting high ratings for Information and Communication).

10.9 (Communication Devices). Each of the four surveys supports the need for improved communication (see especially Section 1.5 above). If devices can accomplish such improvements, they will likely be welcome. Recommendations for research in this area appear in MID, B-3 and RIGHTS, Art. 7.

11.0 Technology and Data Systems

11.1 (Registers). See Sections 1.2, 1.3, and 1.4 above.

11.2 (Data Collection and Recordkeeping). See Section 11.1 above.

11.3 (Interagency Cooperation). With respect to data collection and dissemination, the desirability of interagency cooperation has been discussed in Sections 1.2, 1.3, and 1.4 above. See also Section 12.0 below.

12.0 Interagency Cooperation

The deaf-blind population is numerically insignificant within any State. At the same time, adequate programming for deaf-blind individuals at every developmental stage is relatively expensive. To assure that deaf-blind services receive appropriate attention in the budgeting of each social service agency, the responsibility should be centered Statewide in a single agency or individual who can be held accountable for program gaps and who can avoid unnecessary service duplications.

A further problem that would be resolved by adoption of this policy is the difficulty deaf-blind persons find in locating the appropriate agency designated to serve them. The deaf-blind individual can waste a great deal of time being shunted from agency to agency; some fail to make any appropriate contact, become discouraged, and do without, even when provisions for their needs are available in their State. A State coordinator could also function as the deaf-blind persons' ombudsman, striving to see that they receive proper treatment from the various agencies with which they must interact and assuring a continuum of services through interagency agreements.

The reports that have been reviewed in Chapter IV support this reasoning. Three suggest the development of model plans as a vehicle for achieving interagency cooperation within States (MSA, pages 29, 30, and 37; MID, B-15 and C-12; and NOW, R-3). Emphasis on representation of deaf-blind persons at the decision-making level occurs in several reports (FORUM, 5; NA, 3.0, 3.1, and 5.1a; MID, B-2; and NOW, R-1). The criticality of cooperation between Education and Rehabilitation is urged by AIR, 4; and MID, A-10, A-11, and A-12.

12.1 (Medical/Dental Agencies), 12.2 (Social Agencies), 12.3 (Education Agencies), 12.4 (Vocational Agencies), 12.5 (Rehabilitation Agencies), 12.6 (Other State/Local Habilitation Agencies), and 12.7 (Other Agencies). See Sections 3.4 and 4.4 above.

13.0 Public Awareness and Policy Development

13.1 (Involvement of Appropriate Federal, State, and Local Agencies). Agency representatives feel it is important to retain at least some elements of the programs that led to the mushrooming of educational efforts on behalf of deaf-blind children (Chapter VI, "Opinions of Major Problems/Successes: Administrators").

13.2 (Legislation). Not covered in the four surveys. References to legislation in the literature are only in connection with funding.

13.3 (Appropriations). The Administrators are most concerned about funding (e.g., Section 13.1 above). Adults and Parents mention financial support as a serious problem (Tables 6.23 and 6.33). Five reports recommend federal support for deaf-blind programs (AIR, 1, 3, and 4; FORUM, 5; NA, 2.3b and 3.1a; MID, A-1 and B-19; RIGHTS, Art. 4). Three reports advocate federal allocations for services beyond the capability of States to provide them (AIR, pages 24 and 25; NA, 8.C; and MID, B-12). Table 4.4 shows that, of 20 respondents asked, only 2 thought funding would be adequate in the next five years.

13.4 (Information Dissemination). The Adults give information a high priority (Table 6.33).

13.5 (Definitions). See Section 1.0 and the ensuing discussions in Sections 1.2, 1.3, and 1.4 above.

14.0 Consumer Involvement

Deaf-blind persons are a major resource in resolving the problems of deaf-blindness. As has been demonstrated so often by other disability groups, consumer involvement can be a significant ingredient in determining program success. Parents of deaf-blind children should have more visibility on boards of agencies serving deaf-blind persons and should have a greater share in decision-making.

14.1 (Advocacy). This does not appear to have a high priority among the samples interviewed.

14.2 (Service Providers). Administrators and Teachers are not satisfied with the degree to which parents now participate in their children's eduation (Tables 6.11 and 6.21). Especially note that Administrator's regard parents of older students to be least interested and least participating in their children's education (Table 6.11).

14.3 (Families of Deaf-Blind Persons). Parents appear satisfied with the degree to which they presently participate in their children's education (Table 6.21).

14.4 (Deaf-Blind Individuals). The Adults did not mention participation in education and rehabilitation as a problem or as a specific desire. However, two reports stress the importance of consumer involvement in decision making (MSA, page 38, and MID, B-7).

Chapter VIII
Suggested Policies and Options for Implementation

The findings presented in the preceding chapters may be construed in many different ways. In preparing the following suggestions for policies to meet the needs of deaf-blind people, we recognize that facts alone do not determine governmental and public reactions to particular situations. Priorities for any one group of citizens must be assigned within the total priorities for the nation. This report, however, directs its attention solely to the deaf-blind population. The recommended policies and accompanying suggestions for their implementation are consistent within that limited frame, though they may be too broad in scope and overly ambitious, given the entire education-rehabilitation picture---a scope far outside the purview of this assignment.

The source for each policy statement is indicated by reference to the relevant discussions in Chapter VII. By referring back to those sections, the reader can identify the specific data that generated the recommended policy. References are by section number, thus: 1.0 is the first section of Chapter VII and 14.4 is the last. To the extent possible, the implementation strategies also arise directly or are implied from the various data already presented. By consulting the appropriate sections of Chapter VII indicated in the references given in the policy statement, the reader will be led back to the extended discussions in the data sections of the report.

It should also be emphasized that a clear division has been made between policy statements and the implementation strategies. A single policy may have several management options by which it can be achieved, and the same policy may be implemented in different ways. The implementation options that follow each policy statement are numbered to correspond to it, allowing for more than one strategy to be suggested for each policy statement. Where more than one option appears following a policy statement, the order is roughly hierarchical; i.e., the first option, it is suggested, should be adopted before the second, and so forth. However, this ordering, again, is merely advisory. In drafting the suggestions for implementation, care has been taken to avoid being overly specific; the suggestions are essentially schematic and illustrative. Any particular policy might lead to many more or fewer steps than those that have been presented below. It should be stressed, again, that the suggested options for policy implementation are neither intended to be exclusive nor exhaustive. They will, it is hoped, further explicate the policy statements and add to their value for future planning.

A. The federal government should assume the responsibility for annually determining the size and characteristics of the deaf-blind population.

References: Sections 1.2, 1.3, and 1.4. (See also Policy Statement E below.)

A.1. The Department of Education to convene a task force on the definition of deaf-blindness and related terminology.

The task force should include other federal agencies apt to have an interest in this matter, e.g., Department of Health and Human Services. The group would consider the various definitions in use, select one, and publicize its choice. Definitions are based upon arbitrary decisions. They succeed insofar as they are accepted by those who are concerned with their application and to the extent that they are comprehensible and easily applied (the latter two conditions not being easily separable from the former one). The task force should strive to have the definition recognized in federal legislation and regulations, so as to ensure its broadest possible adoption. Examples of some related terminology that would also be usefully defined are blindness and deafness.

A.2. Develop and maintain an appropriate register of deaf-blind persons.

Helen Keller National Center for Deaf/Blind Youth and Adults has not had the financial and technical resources for building a register that meets fundamental requirements for a statistically valid basis for determining the size and characteristics of the deaf-blind population. It has merely been directed to 'keep one,' without having had the trained personnel to plan it. HKNC is the victim of the naive notion that all that is required to establish and maintain a register are good intentions. In fact, demographers regard the register as a sophisticated tool with which to supplement the morbidity survey.

Alternatively, this critical statistical function might be separated from the direct service role assigned to HKNC. The Deaf-Blind Register might be kept by another agency that already has the requisite personnel to design and maintain it and that has a commitment to morbidity statistics. Such an agency might be the National Institute for Neurological and Communicative Disease and Stroke, or the task may be opened to bids from any appropriate organization that desires to undertake it.

Provisions should also be made to retain the register of deaf-blind students that has been developed by the Regional Programs. The merging of that register with the adult data is an important step.

A.3. Conduct on a four- or six-year cycle morbidity surveys to validate the register and determine the extent to which it is 'complete.'

The morbidity survey and the register supplement each other. It takes both to arrive at statistically reliable estimates of rare populations, such as the deaf-blind population, at reasonable cost. The logic of this approach is presently followed by the U. S. Bureau of the Census with respect to a number of small groups within the population, and a modified form has been specifically tested with the deaf population.

A.4. Encourage social service agencies to use the register to improve their services.

The register provides information that can aid casefinding without breaching confidentiality (see text). The register is also invaluable in assessing program efficacy.

A.5. Annually publish the statistics from the register, in order to acquaint researchers, program evaluators, administrators, and the general public with size and characteristics of the deaf-blind population.

Only group data would be released, so there is no question of breaching an individual's confidentiality. With respect to publication, professional journals would be used, to avoid any added costs.

B. A continued federal presence is desirable in the education of deaf-blind children and youth.

References: Sections 1.1, 8.7, 9.2, 10.0, and 13.3.

B.1. Seek Congressional action to continue the federal presence in the education of deaf-blind children and youth.

The nature of the Congressional action may take several forms, some of which are described in the immediately following recommendations. These suggestions recognize that the day-to-day costs of instruction are properly the responsibility of the States. The federal allocations should be used for those support services that single States cannot provide efficiently. Since these funds represent only a portion of the educational costs for deaf-blind students, the appropriation can be seen as providing a multiplier effect toward paying for their special education. Furthermore, since the federal government would be offering funds to the States, it would have the opportunity to continue monitoring their programs. This latter function can be highly beneficial to the widely scattered facilities for this low-incidence student group, providing guidance and encouragement for the continuation of highquality programming. See Section D for further explication.

While the federal presence is important to furthering the education of deaf-blind persons, it does not preclude efforts by nongovernmental agencies. Indeed, one federal role can be to encourage private involvement in the education of these severely handicapped individuals. The government can provide mechanisms for the coordination of its programs with those developed by nongovernmental agencies and individuals, in order to maximize the impact of these initiatives.

B.2. Request specific funds to support educational research to improve the instruction of deaf-blind students.

SEP must divide its slender research and development funds among many disability categories. To relieve the strain on its budget, SEP needs specific funds to increase its research on the education of deaf-blind children, to further the development of educational methods and materials, and to offer incentives to develop research personnel.

B.3. Request specific funds to support the preparation of personnel to work with deaf-blind persons.

Few facilities exist for the preparation and continuing education of personnel who work with deaf-blind students and adults. Granted the highly specialized nature of their work, these professional and semi-professional individuals are in need of extensive preparation for their assignments and for ongoing training to maintain their skills and their morale. RSA and SEP's training funds are already stretched thin. Earmarked funding would relieve the budget pinch.

Consideration should be given to educational programs that will develop the educational leadership that is presently in short supply. Also, short-term training, especially for rehabilitation personnel would be welcome. Such training should be coordinated with the efforts made by HKNC, to maximize the impact on the field.

B.4. Continue the joint SEP-RSA efforts development of procedures and practices leading to the coordination of every deaf-blind individual's IEP and IWRP.

Such a program is underway within the two agencies. It is important that the fruits of such efforts be expeditiously shared in the field.

C. Encourage States to coordinate deaf-blind services at a decision-making level within their hierarchy of social services.

References: Sections 1.2, 1.3, 1.4, 3.4, 4.4, and 12.0.

C.1. RSA and SEP to prepare model strategies that will encourage each State to establish a central office or individual responsible for the coordination of all efforts to serve deaf- blind individuals.

The dispersion of authority for services for deaf-blind persons from State to State inhibits the proposal of a single recommendation for accomplishing the objective embodied in Policy Statement C. The relations between Special Education and Rehabilitation vary from State to State. States that serve deaf-blind people through an agency for the blind should be approached differently from those that do not have these agencies. Sixteen States now have agencies exclusively concerned with deafness, again requiring a different approach from those lacking such agencies.

One approach that has had success with State VR agencies is to recommend to the States a model plan that incorporates this particular feature. The conceptual plan conceived for this project provides a framework that may be useful in preparing a model program. Through workshops and publications, States would be encouraged to voluntarily adopt the plan in accordance with local conditions. In most instances, implementing this policy will require the actions of State legislatures. This strategy (preparing a model for States to adapt and adopt) has also succeeded in other areas, such as, automobile and driver licensing. Despite the complexity of the problem, the goal can be achieved in at least some of the States, i.e., to have a Statewide Coordinator of Services for Deaf-Blind Children and Adults.

D. Programs for deaf-blind children's parents should be established to provide them with education and respite care, two areas now seriously lacking.

References: 8.0, 8.2, and 8.7

D.1. Seek federal and voluntary support for respite care of deaf-blind individuals.

Each State should design programs to accommodate parents who feel in need of relief from the constant demands of their severely disabled children. These programs should meld governmental and voluntary efforts.

D.2. Provide funds for programs to educate parents of deaf-blind children about their children's condition, the remedial steps that can be taken to alleviate the consequences of that condition, and the prospects for the children's future.

Typically, parent-education programs are directed at the parents of young disabled children. However, the programming should envision periodic contacts with the parents over their children's development for two reasons: (1) at the earliest sessions, parents are usually still adjusting to the realization that their children are deaf-blind; they later report that they were too emotionally upset to concentrate on what they were being told, though they seemed attentive; (2) the parents need different kinds of information and reassurance at different stages in their children's development; it does little good to tell the parent of a three-year-old deaf-blind child about the strategies that are most likely to be successful in dealing with adolescence. Programming, therefore, should be designed in stages that are most likely to be in consonance with the parents' interests. The term 'education' should be broadly construed to include counseling, especially for those parents whose children have progressive disorders (e.g., Usher's syndrome) that will place future burdens on the parents for which they need to be prepared, in order to relieve the additional stress they will face along with their afflicted offspring and communication training.

E. Every State needs to establish and maintain vision and hearing conservation programs, especially for persons who already have sensory impairments.

References: 2.1, 2.2, 2.3, 3.1, 4.1, 4.2, and 10.1. Also see Policy Statement A above.

E.1. In regulations that govern the education of handicapped children, require audiological and ophthalmological examinations at periodic intervals.

The lack of appropriate programs for vision and audition care does not seem to be a matter of funding; schools can usually find the money to support adequate detection of sensory defects. What seems to be lacking is sufficiently high priority for these services in the care of those children who already have a disability in one sense. Early detection of incipient or impending disability in a second sense may ameliorate the effects of the additional disability or, in some instances, may prevent the deterioration of the second sensory disability. Educators should be encouraged to maintain the programs they have and to add to them as indicated. Critical to the effectiveness of programs of auditory and visual diagnosis is entering the results in the students' records and reporting significant findings to (a) parents and (b) the deaf-blind register, when those findings indicate that a child meets the criteria for diagnosis as a deaf-blind person [see A above]. Such reporting should be encouraged by the regulations.

E.2. Require schools for deaf and blind children to include in their curriculums information on the care of the intact sense.

SEP can implement this provision by underwriting the preparation of appropriate curricular units.

E.3. Encourage adult rehabilitation programs to provide thorough examinations of the complementary sense in cases of deaf and blind clients, at the time they are evaluated for service.

RSA already has a regulation requiring that all deaf clients be given a careful ophthalmological or optometric examination as part of their evaluation. Similar provisions have been made for blind and deaf-blind clients. A study needs to be made of the extent to which these regulations are being followed and, where they are not, of the reasons why they are not being carried out.

F. A federal program of job development and job placement is urgently needed to supplement the efforts of State Vocational Rehabilitation agencies and Commissions for the Blind.

References: 4.0, 4.6, 7.2, and 8.4.

F.1. Request Congress to appropriate funds to encourage local and voluntary efforts that develop job opportunities for and job placements of deaf-blind adults.

Precedents already exist for programs that generate vocational openings for handicapped persons; however, deaf-blind persons have not had full benefit from such programs. What is needed are funds earmarked for them. Managed by RSA, such funds can exert a multiplier effect on the local and voluntary initiatives already being made.

F.2. Initiate training for VR counselors that will inform them about the abilities of deaf-blind persons and will motivate them to seek jobs for them.

Few VR counselors have experience, especially successful experience, in placing deaf-blind clients. Yet, there are success stories, and there are opportunities for placements. A major barrier to deaf-blind persons' placements is the counselors' failure to see their clients as job-ready when, in fact, they are. Counselors also need more information about federal tax incentives for corporations that hire handicapped workers and who make modifications to accommodate severely impaired workers. Evaluating counselor performance with weighted closures may also encourage more attention to deaf-blind clients.

G. Increased attention should be given to developing independent-living and alternate-living programs for deaf-blind adults.

References: 5.0, 5.1, 5.2, 5.3, 5.4, 5.5. 6.0, 6.1, 6.2. and 7.0.

G.1. Urge Congress to appropriate funds to implement the provisions for independent living contained in P.L. 95-602.

While independent-living services have been authorized by Congress, funding has been too little to effect much change in the conditions of many deaf-blind adults who need the facilities that could be provided, if funds were available.

H. Research efforts must be funded to identify, invent, and evaluate new methods for overcoming the disadvantages of deaf-blindness.

References: 1.5, 3.7, 10.0, 10.1, 10.2, 10.3, 10.4, 10.5, 10.6, 10.7, 10.8, and 10.9.

H.1. Request that Congress appropriate funds for research on and development of communication by deaf-blind persons.

Without earmarked funds, little research effort can be expected on the esoteric problem of communication faced by deaf-blind persons. The need for improvements in this area is only equalled by that for transportation improvements. By 'communication' should also be understood warning and signalling devices, as well as those that provide for higher levels of information transmission.

The relatively small size of the deaf-blind population also means that development funds must be allocated to assure that inventions resulting from research will either enter the marketplace or will be made available to deaf-blind persons on a subsidized basis.

H.2. Request that Congress appropriate funds for research on and development of transportation for deaf-blind persons.

As with communication research, the research on transportation improvements for deaf-blind persons merits earmarked funds. Some of the research, if not all of it, must be directed to assisting deaf-blind persons to accommodate to their environment more effectively, since it is unlikely that great concessions can be made in every location for the relatively small group of people involved. Enhancing mobility training would be among the top research priorities. Lack of adequate mobility is one of the most common reasons for deaf-blind persons to fail to hold employment they have secured. See Section F.

I. Governmental and voluntary support for recreational programs and services designed for deaf-blind persons should be increased.

References: 6.0, 6.1, 6.2, and 6.3. [See also Policy D.]

I.1 Urge the funding of recreational programs and services authorized under P. L. 95-602.

Congress has authorized adult recreational programs in connection with the rehabilitation of severely disabled individuals. This section of the legislation recognizes the importance of leisure-time activities in the total economy of the disabled individual's life functioning. The maintenance of a wholesome balance between vocational and recreational activities is within the purview of Rehabilitation. States should be encouraged to establish recreational programs for deaf-blind persons.

I.2. Develop volunteer efforts on behalf of the recreational needs of deaf-blind people.

The resources of the deaf-blind adult's community can be mobilized on behalf of that individual. Volunteerism, to be successful, requires training for the volunteers and supervision of their activities. These aspects can be provided through grants to States that support the development of such programs and foster their continuation.

J. The nature of the deaf-blind population demands that a concerted effort be made to provide elder care.

References: 7.0, 7.1, 7.2, 7.3, 7.4, 7.5, 7.6, and 7.7.

J.1. Develop interagency cooperation to initiate voluntary and governmental programs to meet the special needs of elderly deaf-blind people.

SEP and RSA have a great deal of expertise that could contribute importantly to programs funded by the Administration on Aging, the Department of Housing and Urban Affairs, and the Social Security Administration, as well as nongovernmental agencies and individuals. Working together, these agencies and individuals can put in place the nutritional, housing, and recreational programs that are needed by elderly deaf-blind persons.

K. The assistance of deaf-blind consumers should be sought in planning all programs specifically directed at serving them.

References: 14.0, 14.1, 14.2, 14.3, and 14.4.

K.1. Establish an advisory group of deaf-blind persons to counsel SEP and RSA with respect to programming for deaf-blind persons.

Ongoing groups of advisers can be highly effective in providing attitudes about and information related to proposed strategies that are aimed at like-minded persons. In the case of deaf-blind individuals, their condition makes such input all the more valuable, because the condition is rare, and research into its ramifications is, as yet, sparse, rendering the opinions of deaf-blind individuals potentially very helpful in avoiding tactics and strategies that would not be acceptable and in pursuing vigorously those that would. The insights of deaf-blind persons are the best guides to planning for the deaf-blind population.

K.2. Conduct periodic interview surveys to determine the trends in needs and accomplishments of the deaf-blind population.

As has been demonstrated, deaf-blind persons have a great deal to report about their circumstances, and they are eager to make their views known. The keys to successfully interviewing them are interviewers who are highly skilled communicators or versatile manual interpreters.

L. Extend educational support for deaf-blind students from the present upper-age limit of 21 years up to age 25 years.

References: 3.5

L.1. Amend the regulations governing federal funding of educational programs for deaf-blind students.

Legal counsel should be sought to determine whether or not Congressional action is required to extend the limits of the age range for support. If Congressional action is necessary, then it should be sought.

L.2. Initiate programs to encourage the States to adopt the increased age limit.

Gaining the acceptance of the States for this policy change will require active leadership from the Department of Education. The States may be reluctant at first to assume the additional expense of carrying out this provision, even though that expense in any single year is apt to be relatively small for a particular State. Working through NASDSE, the Department can be assured that its case will reach State departments of education. Additionally, SEP may wish to enlist broader support by acquainting the public and professionals with the rationale for this policy.

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